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## Commentaries

# Localizing the Wandering Uterus

**Conversion disorders have been** recognized forever although not formally studied until the great French neurologist, Charcot, turned to this problem in the mid 19<sup>th</sup> century. The patients were predominantly women, perhaps all women, who manifested a variety of clinical signs that could not be explained by any known derangements of neurological structures. Freud, who studied with Charcot, developed an interest in this area, later publishing the case of conversion-weakness in Anna O. Anna O, of course, was cured by psychoanalysis and went on to a prominent career as a social worker.

The term “conversion disorder,” which has been used interchangeably with “hysteria,” refers to the presumed mechanism by which non-organically explicable neurological abnormalities result when emotional distress is allegedly “converted” into physical manifestations. The term “hysteria,” which predated Charcot, is derived from the Greek term for uterus. It was used to describe these disorders because they were thought to occur only in women, and were ascribed to a problem with the uterus, which was thought to wander.

Conversion symptoms are so common that they are discussed in the vernacular in such phrases as, “so-and-so is a pain in the neck” (or some other place). In short, “so and so” causes so much aggravation that one experiences his presence as physically painful. It is common to blame headaches, for example, on stress at work, difficulty with relatives, etc. It is unlikely that anyone doubts that stress may cause pain in vulnerable people. Yet the notion that stress may cause weakness, numbness, blindness, muteness, tremors, impaired walking, or seizures, is accepted more in the general sense than in a specific case. “Yes, I think that stress may cause these problems in some people, but not in me.”

A few decades ago, before the era of modern imaging and invasive testing, several studies reviewed the long-term out-

come of patients who had been diagnosed with psychogenic explanations for their symptoms and signs. They found that from 30-50% ultimately *were explained* as the result of organic lesions. Neurological patients were found to have MS or unusual, but clearly organic forms of epilepsy. Inflammatory bowel disease explained many with non-specific GI symptoms. Systemic lupus erythematosus and other autoimmune disorders became apparent. Metabolic derangements became identifiable, and these, in retrospect, did explain the earlier symptoms. This undermined clinicians’ confidence in their diagnoses, particularly psychiatrists who were put in the difficult position of trying to “cure” someone of a presumed psychogenic disorder that later turned out to be multiple sclerosis or a brain tumor. However, in recent times, similar studies have revealed an amazingly low incidence of mis-diagnoses. The vast majority of current diagnoses of non-organic disorders are, it seems, correct. The problem thus moves from, “is it organic?” to “how did this happen?” and “what to do about it?” And the answer is, unfortunately, not known. Psychoanalysis has been more helpful in explaining than in treating it.

Since I’m a movement-disorders specialist I know most about conversion disorders in this area. The diagnosis of psychogenic disorder is made in about 5% of new patients referred to movement-disorder centers in the western world. This certainly underestimates the problem because many of the disorders are transient and resolve before the appointment to the specialist’s office. My experience doing general neurology consults in hospitals suggests a percentage quite a bit greater than 5%. It is not terribly uncommon to give tPA, for example, to patients who were thought to have had strokes, but actually had psychogenic weakness. I’ve seen one patient who has had tPA twice for psychogenic “strokes.”

The natural history of conversion disorders in general is interesting. The vast majority resolve without treatment in the first few weeks, while those that persist for several months generally persist forever. These are often disabling, and no treatment is known to be effective. The patients generally do poorly. The neurologist dismisses them with, “no neurological disorder;” then the psychiatrist dismisses them with “no psychiatric disorder.” Only recently have some neurologists followed these patients, even if the etiology of the disorder is psychiatric, just as we follow people with untreatable degenerative disorders. This is support and is important, but it is not treatment, at least not specific treatment.

While many of these patients share a variety of common psychiatric comorbidities, such as childhood abuse, personality disorders, post traumatic stress disorders, not all do, and many, on the surface, appear to not have much in the way of psychiatric dysfunction. This, of course, makes life hard for the psychiatrist and, worse for the poor patient.

In recent years, studies have tried to figure out “how” rather than “why” conversion disorders occur, by using fMRI, a crude measure of brain activity, while the patient has conversion symptoms, and comparing the results to normal controls feigning the same disorder. In one study, the conversion patients had intermittent tremors and the fMRI were obtained while the patient had the conversion tremor and then again when the same patient voluntarily mimicked the tremor, thus acting as his own control. The fMRI patterns differed when the conversion disorder patients had their conversion-tremor, presumably voluntary but unconscious, from when they feigned the exact same tremor. This implies that physiological underpinnings explain how some patients develop neurological symptoms which are generated unconsciously. These physiological alterations will not explain why some patients develop these problems but may, in time, suggest how to treat them. It is not clear in this early stage whether this imaging modality will allow us even to diagnose the problem.

These studies are important because conversion disorders are common, confounding to all involved and may provide insights into the dynamics of unconscious

motivations. The different symptoms have been associated with different brain alterations. No single region has been implicated to suggest that there is a region devoted to “self-awareness.” The data provide a philosophical conundrum. How can an unconscious disorder be “non-organic?”

– JOSEPH H. FRIEDMAN, MD

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Conflicts: In addition to the potential conflicts posed by my ties to industry that are listed, during the years 2001-2009 I was a paid consultant for: Eli Lilly, Bristol Myers Squibb, Janssen, Ovation, Pfizer, makers of each of the atypicals in use or being tested.

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## Ancient Speculation On the Seeds of Pestilence

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**Most noteworthy scientific discoveries represent dramatic** departures from prevailing dogma, courageous leaps into unexplored territory. But the germ theory of disease is not one of those quantum leaps. Without lessening the seminal contributions of Louis Pasteur (1822 – 1895) and his coworkers, it must nonetheless be recognized that many prior thinkers, centuries before Pasteur, had envisioned the possibility of an invisible *something* that was transmitted from the already-sickened to those about to fall sick; that some agent – if not visible at least corporeal – accounted for the dynamics of communicable disease. Many speculated over the centuries, but it was Anton Leeuwenhoek (1632 – 1723) who provided the instruments to observe these erstwhile invisible creatures and Louis Pasteur who provided the incontrovertible proof of their vital role in the causation of many human ailments.

In the absence of suitable scientific instruments, how might a physician in the year 180 CE explain the phenomenon of a contagious disease? He will observe, first, that certain diseases such as phthisis (tuberculosis) or ophthalmia (trachoma) readily infect those who come near while sufferers of dropsy or apoplexy do not seem to convey their ailment to others solely by proximity. An analogy was made to the phenomenon of magnetism: those things proximal to the magnet were attracted while those more distal were not. Still, how does the contagion get to be transmitted from one human to another? What specifically is being transmitted? Something physical? Or metaphysical?

This hypothetical physician's thinking must then confront an ontological question: Is the disease initiated by divine intent or by earthly cause? If it is caused by celestial intervention, then the ailment lay beyond the physician's earthly remedies. And so his thinking then gravitates toward the alternative: that the contagion is incited by a secular mechanism.

If earthly, might it be in the form of a vapor, such as the putrid mists emanating from swamps? Certainly the idea of morbid vapors – called miasma – causing malaria (Italian for bad air) was a widely accepted etiologic premise. To cite Lucretius (99 – 55 BCE), “When the deadly seed flying about the atmosphere come together, the air putrifies and becomes dangerous.” Three centuries earlier, Thucydides (460 – 395 BCE), historian of the plague of Athens, accepted that “The circumambient air carries certain seeds of plague” and presumed, further, that breathing in the putrid exhalations of

swamps and dead bodies produced the hot pestilential atmosphere that provoked the great plague.”

So the mists of the evening, generated by swamps, yielded bad air. But what was the inherent badness in bad air? Was it something spiritual (as in “Satan's pestiferous breath”) or something particulate? And could invisible things still be particulate?

Marcus Varro (116 – 27 BCE) was more specific in his speculation. He declared that “swamps bred invisible animalcula (*animalia quaedam minuta*) which on being breathed through the nose and mouth cause disease.” Certainly a wild hypothesis singularly free of any supporting evidence.

Claudius Galenus, known as Galen, was born in 129 CE in the Greek colony of Pergamon in Asia Minor. He was the son of a wealthy contractor who spared no expense in seeing that Galen was well-educated in philosophy and eventually in medicine. Galen traveled widely, wrote extensively, lived through the great Antonine plague, was personal physician to both gladiators and Roman emperors including Marcus Aurelius, and was Europe's most authoritative physician for over a thousand years after his death.

Galen wrote extensively, and reflected deeply, on the nature of contagion and the mechanisms underlying the spread of pestilential diseases; and further, whether this represented a tangible – if invisible – seed; or, alternatively, whether it was a miasma, a formless but deadly vapor which attacked all who inhaled its miasmatic poison. He favored the idea of a particulate seed, but it is not clear whether he construed “the disease seed” as a literal entity or merely a figurative metaphor. Galen went a step further proposing that the development of a disease required both the initiating seeds as well as a systemic alteration making the human more receptive, more vulnerable to the workings of the invasive seeds. Galen envisaged various environmental influences, such as excessive consumption of wine, as predisposing factors.

When working with ill-formed ideas and groundless speculations – and in the absence of substantive observations – scientists tend to seek analogies and metaphors. And in their gropings to explain why some fevers seem to be transmitted from person to person by proximity, they sought out happenings in their daily lives that bore a resemblance to the transmission of pestilence. The seed, an inconspicuous little

object, came to mind as a fitting metaphor since it is a living thing which, under appropriate circumstances, grows into something quite mammoth. And some courageous thinkers bestowed animal life to this hypothetical seed, referring to it as an animalcule.

Thus did thinkers, from poets to physicians, think of the possibility—just the possibility—that there exists a world of invisible things; and that populating this world are microscopic creatures capable of corrupting the human body in a phenomenon called contagious disease. Two millennia ago Pliny (23 – 79 CE) wrote: “Nature is to be found in her entirety nowhere more than in her smallest creatures.”

– STANLEY M. ARONSON, MD

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Stanley M. Aronson, MD, and spouse/significant other have no financial interests to disclose.

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## **The Ecology of Neonatology In Rhode Island: Improving Care For Newborns**

*Marcia W. VanVleet, MD*

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*“In the planning and designing of new communities, housing projects, and urban renewal, the planners, both public and private, need to give explicit consideration to the kind of world that is being created for the children who will be growing up in these settings. Particular attention should be given to the opportunities which the environment presents or precludes for involvement of children with persons both older and younger than themselves.”*

– Urie Bronfenbrenner <sup>1</sup>

**Neonatology has been making improvements** in short-term outcomes since its “infancy” as a board-certified subspecialty in the 1970s. Most remarkable are the improvements in the survival of the most premature and those born at very low birth weights. However, through the articles contained in this special edition, you will realize that those in newborn medicine are now looking beyond the individual infant in its acute, critical state to the newborn’s development over time.

The “father of Head Start,” Cornell University child psychologist Urie Bronfenbrenner introduced (also in the 1970s) a theory of the ecology of human development. His theory stretched the psychologist to look beyond the individual child to the systems that support a

child. His theory can be represented as a series of spheres or concentric circles expanding from the infant or individual child to those larger, like the school system and legislation. Within the representation of the theory the individual child is in the center, with the circles or systems defined as; 1) a *Microsystem* with direct interactions with family, siblings, and peers, 2) an *Exosystem* with extended family, parent’s work environment, mass media, neighborhood and school board, and then 3) *Macrosystem* with aspects of society such as the history, laws, culture, economic and social conditions. A 4th system is referred to as the *Mesosystem* which is the interactions or connections between Microsystems. Since the original introduction the theory has been refined to include a *Chronosystem* which captures the patterns of change over a person’s lifetime or sociohistorical across time (e.g. divorce in a family).<sup>2</sup> Bronfenbrenner was in essence moving the field of human development from the traditional one-setting approach towards a child-centered approach across all settings.

Similarly, in Rhode Island we in neonatology or newborn medicine are approaching the improvement of neonatal outcomes across many settings and for longer periods of time. (Figure 1). For example, you could look at the construc-

tion of the new (**Neonatal Intensive Care Unit**) NICU as a direct intervention to improve the infant’s first *microsystem* with its family-centered approach. From here you can look at our developmental interventions with their emphasis on touch and complementary modalities as strengthening the skills of a family to meet the individual child’s needs, but also as strengthening the *mesosystems* relationships between medical care and the family. Teaching these care-augmenting techniques and skills brings to mind a statement by Bronfenbrenner that, “No society can long sustain itself unless its members have learned the sensitivities, motivations, and skills involved in assisting and caring for other human beings.”<sup>3</sup>

In this special edition you will see an example of how *macrosystems* with legislation developing the state-wide systems-based approach to hearing screening can directly impact the child. You will read about our use of the latest simulation technology to improve delivery of care, to diagnosis problems areas, to establish new processes, and to train staff, before our big move. Then finally you will read how we are continuing to follow these smallest and most vulnerable newborns over the course of their childhood, as they transverse their expanding ecology, and then using this information to improve the acute care we

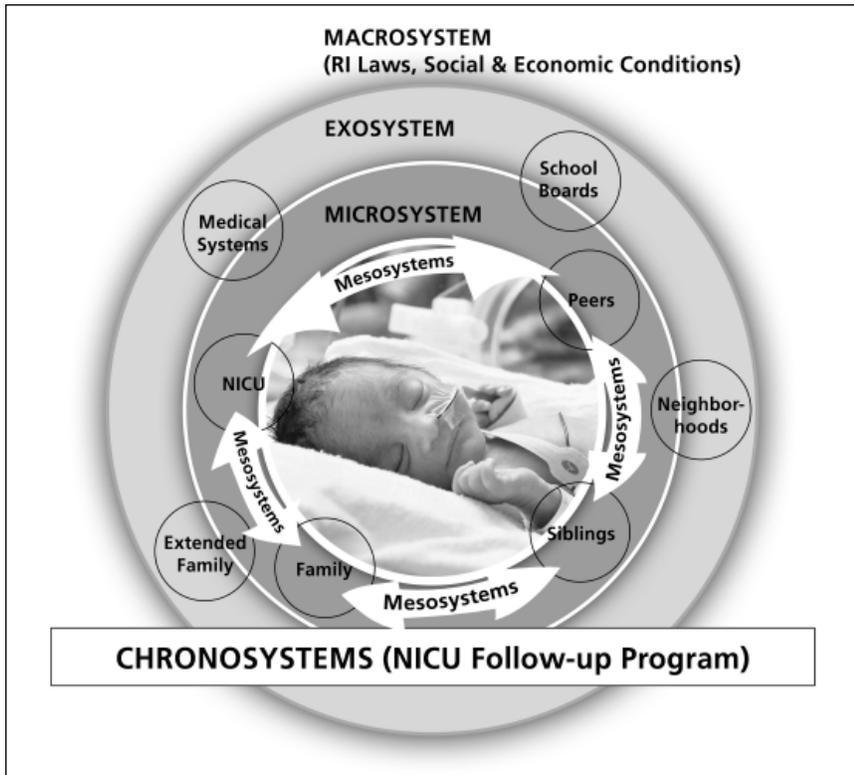


Figure 1: Ecology of Neonatal Development in RI (Adapted from Urie Bronfenbrenner)

provide today. One aspect of our follow-up program could be seen as tracking these infants' outcomes to see how NICU experiences translate as a *chronosystem*.

I am drawn to Urie Bronfenbrenner's ideas about child development now in R.I. because of his emphasis on society's responsibilities, and the need to invest both financially and otherwise to help children develop to their best potential. He stretched the responsibility beyond those who work directly with children to those who plan and build the places children will be (see highlighted quote). It is this

responsibility that we embraced in developing and designing the new NICU and in the constant improvement in the other programs we provide for infants and their families. These are exciting times to be caring for newborns, with opportunities to build buildings to better meet the needs of children, and to build systems that better support those who care for children. But it is especially exciting to think about how the care we provide for these newborns is rapidly evolving through many improvement processes to better meet the needs of Rhode Island's smallest and most vulnerable patients.

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# Building For the Future of Rhode Island's Newborns

James F. Padbury, MD, Marcia W. VanVleet, MD, and Barry M. Lester, PhD

The discipline of neonatology is recognizing that “best practices” and “standards of care” are necessary to improve outcomes of critically ill newborns.<sup>1</sup> Numerous studies demonstrate that environmental conditions in an Intensive Care Unit can have significant effects on outcome. For caregivers, environment influences their work performance, satisfaction and health.<sup>2,4</sup> For patients, the physical environment can have a profound effect on rate of recovery and development. While these observations are best documented in adult patients, physical and environmental conditions also affect the outcome of critically ill newborns.

In 1986 the Lying-In Hospital moved into the current location to become **Women & Infants Hospital (WIH)** with a 41-bed **Newborn Intensive Care Unit (NICU)**. However, upward pressure on NICU census due to increasing number of deliveries and more importantly increasing survival began not long after that move. Since 1990, deliveries at WIH have increased from 6,500 to nearly 10,000 a year. WIH is a nationally recognized leader in dramatic improvements in survival of extremely low birthweight infants. The most recently published data from the **National Institute of Child Health and Human De-**

velopment (NICHD) Neonatal Research Network in which WIH participates, demonstrates 30-40% of children born at 23 weeks' gestation (only a little over 5 months' gestation!) and greater than 75% of children born at 24 weeks' gestation survive.<sup>5</sup> With these trends the average daily census at WIH since 1995 has risen from 50 to nearly 70 patients per day. This created significant crowding in the NICU. (Figure 1) The existing WIH NICU was an open-bay design with approximately 10,900 square feet. The resulting space around each baby was at best 35 square feet providing significantly less than the present standards of 150-180 sf/baby. It was clear a new NICU was needed.

## THE PLANNING PROCESS: A TEAM EFFORT

A team of inter-departmental, interdisciplinary individuals was mobilized to examine both neonatal and obstetrical service lines with a special emphasis on capacity. These task forces included members of the medical and nursing staff, administrative leadership, support staff and private voluntary physicians who use the facility, with support from outside professional health consultants, epidemiologists and demographers. We

reviewed delivery trends and NICU utilization from 1990 to the present. In order to project future needs, we reviewed the 2000 census and included adjustments for changes in population, race and ethnicity in our community. These data were used to generate different projection “scenarios” for delivery rates and NICU beds, forming the basis for a new 80-bed NICU.

In order to explore the most recent approaches to NICU design and the ‘*models of care*’ that lead to the best outcomes, the team made a series of site visits to selected NICUs across the United States. The team included physician and nursing leadership, staff nurses, architectural consultants, a parent from our *Family Advisory Council* and members of our philanthropy team. The NICU sites chosen were comparable in size, based in an academic teaching program, recently-constructed, and spanned the spectrum of ‘*models of care*’ from open bays to single-family rooms. The programs visited included: Vanderbilt University Children's Hospital in Nashville, Tennessee; Blank Children's Hospital in Des Moines, Iowa; Northside Hospital and Scottish Rite Children's Hospital in Atlanta, Georgia; and Children's Hospitals and Clinics in St. Paul, Minnesota.

Before finalizing the design of the NICU room, the staff and designers built an actual working mock-up room. The mock-up helped the staff to determine the location of materials, the staffing flow patterns, and the best equipment configuration. A staff-wide participatory process enabled acceptance of the single room model concept and was crucial in deciding the final design solution for the NICU room.

## MODELS OF CARE

While it was clear that a new NICU was needed at WIH, it was not clear what physical design and which of the several contemporary styles or ‘*models of care*’ should be chosen. ‘*Model of care*’ refers to the physical environment for the pa-



Figure 1: Crowding in the old NICU at WIH

**Table 1: Guiding Principles for Design of New NICU**

- Family-Centered Care: Parents as “Partners”
- Developmentally Supportive Care Environment
  - Sound and light
  - People, other stimuli
- Promote Clinical Excellence
  - Support medical model
  - State-of-the-art: design, equipment, electronics, information technology (IT), PACS
  - Teaching environment
- Staff Invested/ Involved
  - In design
  - In governance: “collaborative teams”
- Utilize Established Evidence
  - Evidence-based clinical outcomes
  - Safety practices
- Point of Service Care
  - De-centralize services to patient and patient room
  - Rational zone size
  - Minimize patient movement
- Planning/Incorporating Future Flexibility
  - Sustainability: engineering, materials, environment, natural light
- Location
  - Single NICU
  - Adjacency/access from Labor & Delivery
- Unique Institutional Identity
  - Learn from examples
  - Develop W & I model

**Table 2: Design Principles for Design of New NICU**

- Welcoming and Reassuring
  - Sense of openness
  - Preservation of privacy
- Single Family Rooms (Standard of Care)
  - All rooms similar
- Zones within Room
  - Baby
  - Parent (single sleeping accommodation, desk; no toilet, no VCR, no TV, no radio)
  - Staff/ Caregivers
- Clarity of Organization
  - Clear way-finding
  - Smooth flow
  - Ergonomic
- Zoning of NICU
  - Optimum zone size determined based on:
    - Staffing
    - Operations
- Balance Between Staff and Family Needs in Locating Support/Staff Areas
  - On unit
    - Family support area
    - Dirty/clean utility
    - Satellite Pharmacy
    - Staff lounge
    - Conference room
  - Adjacent to or off unit
    - Offices (MD, NM, LCW)
- “Green Design”
  - Maximize use of natural light
  - Evaluate impact on cost and operations
- Sensitivity to end-of-life issues

tient, the way in which the design of the space complements the clinical approach to the patient and family.

One model included open bays where infants are cared for in a large open spaces or a partial modification called a “Pinwheel.” These were similar to the existing NICU at WIH, albeit the new construction would require a much larger open bay.

Another emerging model of newborn intensive care involves “single-family rooms.” This ‘*model of care*’ recognizes that caring for critically ill patients (especially the very young) in a group or cohort can be disruptive to the clinical stability of other patients in shared spaces. This is most apparent in NICUs where stability of vital signs (e.g. heart rate and breathing) is precarious. Even minimal visual, auditory and/or tactile stimulation can result in apnea and bradycardia. The single-family room design has garnered widespread acclaim for its many distinct advantages.<sup>6</sup> These advantages include: 1) less disruption from their neighbors, staff, or other activities related to adjoining patients, 2) better isolation of patients from nosocomial infections, and 3) a unique level of privacy. In addition, the single family room facilitates a truly family-centered approach wherein the families can be present throughout most of the hospitalization becoming partners in the care of their infants rather than episodic “visitors.” We believe the benefits go beyond just the acute medical to improved neurodevelopmental outcomes for the babies.

The results of the visits were surprising and compelling. After completing our site visits, we convened the entire group to synthesize our experiences into a list of “*Guiding Principles*” and “*Design Principles*.” (Tables 1 and 2) While there was some concern that the single-family room ‘*model of care*’ was beyond the scope of the large service at a facility like WIH, after visiting these recently constructed nurseries there was unanimous consensus that it was the only ‘*model of care*’ for WIH. We believe that, before the next decade is completed, this will be the dominant ‘*model of care*’ in NICU design. In the fall of 2006, the American Institute of Architects made this very recommendation.

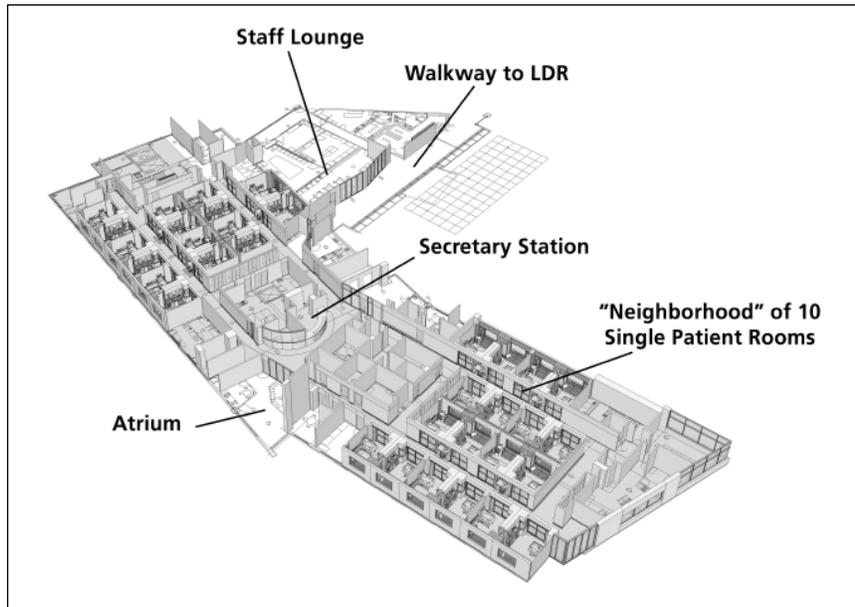


Figure 2: Three-D layout of NICU floor showing clustering of specific programs.



Figure 3A: Nursing charting and work area showing line of site into each room.



Figure 3B: View into Single Patient Room.

## THE NEW NICU AT WOMEN & INFANTS HOSPITAL OF RHODE ISLAND

In order to incorporate all of the clinical programs within 80 single family rooms, the new NICU required more than 56,000 sf. A key requirement for the new NICU was to locate it next to the existing Labor and Delivery Suite (LDR). A single floor NICU would have had an enormous footprint, creating huge distances between service areas. Locating the NICU on two floors reduced that footprint (and cost) and allowed better geographic consolidation. Thus, the New South Pavilion was designed as a 5-story building. The basement houses building support services. The ground floor includes a new lobby, conference center and public support spaces. The new NICU is on Floors 2 and 3. The 4<sup>th</sup> floor is a 30-bed, dedicated high-risk Antenatal Care Unit. The fifth floor houses central mechanical and electrical equipment.

To unite the two NICU floors, the design includes vertical connections utilizing open atriums and stair cases. This architectural design allowed us to provide visible and direct access to program spaces while clustering other essential program spaces, see Figure 2.

### BUILDING ORGANIZATION

Each floor of the NICU is supported by one medical team and is organized into four 10-bed “neighborhoods” for a total of 80 beds. The 2<sup>nd</sup> Floor is immediately adjacent to the LDR and contains clinical programs such as Pharmacy, Respiratory Therapy, and Staff Lounge. Staff/service elevators are at the north entry, while public elevators service the sun-filled central lobbies leading directly to a Secretary Station. Team space is centrally located, supporting terminals for electronic charting, a radiology imaging station, physician on-call room, staff offices and conference rooms.

The 20-bed areas at the North and South ends of each floor have similar elements including a small charting station between each pair of rooms, clean supplies, soiled utility, equipment storage and a family space that intimately accommodates several people. Each area is organized with two neighborhoods. The rooms are staggered to allow maximum visibility,

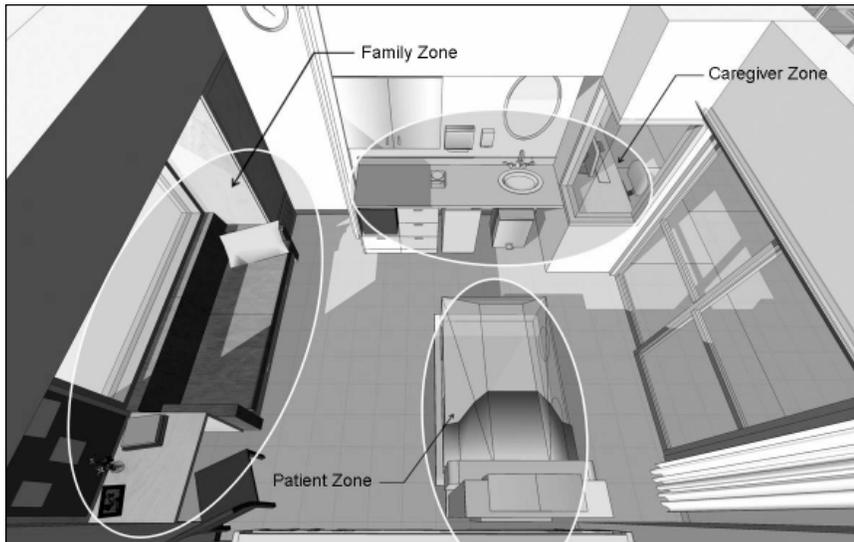


Figure 4: Patient zone, Caregiver/staff zone and Family zone in each room.

staff communication and interaction. Each area has two rooms for twins and three single rooms that when connected can accommodate triplets. None of the rooms are physically isolated, a very important feature for staff. (Figure 3 A & B)

### THE INFANT'S ROOM

Each infant room is 175 square feet and has three distinct zones: Patient, Caregiver/staff, and Family. (Figure 4) Each room provides an opportunity to individualize and personalize its space according to each baby's developmental needs. The patient's room provides the privacy and separation necessary to perform critical procedures, without affecting other infants. The patient zone headwall provides medical gases and electrical services for ventilators, pumps, and monitors.

The caregiver zone has a sink, a dedicated refrigerator and storage cabinets for needed supplies. The family zone accommodates a sleeper for parents, desk and storage, and can be separated by a privacy curtain. Every room has indirect dimmable lighting and temperature control that can be adapted to individual needs related to circadian rhythms and delivery of services.

### FAMILY PARTICIPATION

Space is provided for the family within and outside of their individual rooms. Family members have a place to congregate with other parents or to find respite from the stressful NICU environment. Our family advocates are located in the Family Center

with its comfortable lounge, kitchenette, sibling play area and resource space. The family program elements are distributed over both floors but are all centrally located in an "open atrium" with salt-water aquarium. (Figure 5)

### STAFF SATISFACTION AND RETENTION

Dedicated support spaces, access to daylight, and a less stressful environment are paramount for the well-being and retention of staff. The staff lounge was designed as a comfortable space separate from the workspace to support complementary activity with plenty of natural light to reduce stress in a highly charged unit.



Figure 5. The Family Center which joins elements and interactions between the floors.

### ENVIRONMENTAL DESIGN

We designed the new clinical addition with the goal of improving patient and staff well-being, reducing energy consumption and minimizing negative impact on the environment. We are the first hospital building in New England to achieved certification as a **Leadership in Energy and Environmental Design (LEED®)** at the Gold level.<sup>7</sup> Highlights of the environmental aspect include the use of daylight, water, energy, and materials. Seventy-five percent (75%) of all occupied spaces receive daylight with ninety percent (90%) having views to the exterior. A water management system decreases run-off and treats storm water. Mechanical and electrical systems were designed to improve performance by twenty percent (20%) below US national code. Ten percent (10%) of materials contain recycled content including steel, concrete, linoleum flooring and ceiling tiles. Low-emitting materials were utilized such as adhesives, sealants, paints and carpets. For complete details about the WIH LEED® details, visit: <http://www.womenandinfants.org/body.cfm?id=89&action=detail&ref=354>.

### STUDYING THE IMPACT OF PHYSICAL ENVIRONMENT IN THE INTENSIVE CARE SETTING

We examined published and unpublished data from centers that have recently changed to different 'models of care.' Presently there are no data, which conform to a "gold standard for evidenced-based practice" from a randomized, controlled trial



Figure 6. Family in the new NICU

comparing single family rooms to other models of care. The information to date is either anecdotal or based on retrospective, historical comparisons. The experiences of the units we visited were compelling, nonetheless, documentation according to the best standards of “evidence-based practice” and “evidence-based design” is still lacking.

We are in the midst of conducting a prospective, longitudinal study of the impact of this model of care on outcomes. We believe that infants in the single room NICU will have better medical and neurobehavioral outcomes at discharge than infants in the open bay NICU. Medical outcomes include length of stay, gestational age at discharge, weight gain, illness severity and resource utilization, gestational age at enteral feeding, sepsis and necrotizing enterocolitis. Neurobehavioral outcomes include the NICU Network Neurobehavioral Scale (NNNS) profiles,<sup>8</sup> sleep organization and sleep physiology, infant mother feeding interaction scores, and pain scores. We are carefully collecting prospective measurements in the new NICU. We believe that findings from this study will influence the future of NICU design and model of care throughout the Nation.

### SUMMARY AND RECOMMENDATIONS

Women and Infants Hospital’s design principles reflect a commitment to family centered care, which is at the heart of the Hospital’s *Building for the Future* programs. We have created a welcoming, reassuring

environment with a sense of openness, along with provision of privacy for patients. We have created a contemporary, LEED® Gold certified building that complements our existing structure and promotes our goals in the design. Importantly, we recognized the significance of design in creating optimal safety practices. With the building has emerged among our staff and administration the unanimous view that the single-family room ‘model of care’ is the only model able to meet our goals. There is a balance between staff and family needs in achieving optimal patient outcomes.

On September 16, 2009, the NICU moved into its glorious new space. As we began to fill the new spaces, family members were summoned to be in their new room when their child arrived. By late afternoon, we closed the doors for the final time in the former NICU. Every child was in his/her own room with space for parents to be with them – hold them quietly and bond even in the middle of one of the most high tech units ever built, Figure 6. We have been there for almost half a year now; it is absolutely spectacular! It is quiet, light, and uplifting. The families are happy. The nurses are happy. The trainees are happy. We love our new home...come and visit!

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# Neonatal Screening and Supportive Interventions to Promote Neurobehavioral Development

Rose Bigsby, ScD, and Yun Joo Lee, MD

**Early identification of infants at risk for** problems in neurobehavior and development is an ongoing challenge in pediatric care. Detection of subtle differences in the nursery is challenged by the transient nature of many neurobehavioral signs and by short lengths of stay which limit the ability of pediatricians to perform serial assessments. Most efforts at formal developmental screening in the medical home begin at the 9-month visit, when variations in the progression of motor skills can be reliably detected.<sup>1</sup> Since early intervention optimizes outcomes,<sup>2</sup> the current practice of postponing formal screens until the 9-month visit could result in missed opportunities for developmental support.

## INFANT ASSESSMENT TOOLS

The tools traditionally available for pediatricians' screening in early infancy are known to be poor predictors of long-term developmental outcome.<sup>3</sup> The recent **Neonatal Intensive Care Unit (NICU) Network Neurobehavioral Scale (NNNS)** detects subtle characteristics of infants at risk during their first month, and may reliably predict preschool-age outcomes.<sup>4</sup> The NNNS uses Brazelton's **Neonatal Behavioral Assessment Scale (NBAS)** as a foundation, thus, habituation, orientation, motor and reflex items are included, and items are administered according to the infant's states of arousal.<sup>4</sup> Within this framework, additional NNNS assessment items tap the capacity of high-risk infants to cope with stress and challenge, including preterm infants and those with neonatal abstinence. In a sample of 1248 one-month old infants, NNNS Summary Scores were used to derive five discrete behavioral profiles which related, not only with pre-existing factors like birthweight, **gestational age (GA)**, and prenatal drug exposure status, but also with abnormal cranial ultrasound and neurologic findings. More remarkably, these summary scores were found to be associated with atypical behavioral, school readiness, language and IQ scores through 4 ½ years of age.<sup>5</sup>

The five profiles represent a range of performance, from well-regulated infants who are not easily stressed, to disorganized, excitable infants with poor quality of movement. Infants in Profile 1 (n=276; 22.1%) scored well on focused attention, self-regulation, and quality of movement, required minimal handling to obtain these results, and were not easily stressed. Profile 2 infants (n=409; 32.8%) also had high quality of movement, but otherwise typical scores. Profile 3 infants (n=217 17.4%) required more handling to maintain attention, had higher arousal and excitability and were more easily stressed with handling. Profile 4 (n=274; 22.0%) had average attention and regulatory abilities, but had poor quality of movement, poor tone, and atypical reflexes. Finally, Profile 5 (n=72; 5.8%) had the most atypical scores, with lowest attention, self-regulation and quality of movement, high tone, highest percentage of atypical reflexes, and the most stress signs. Profile 5 infants also had more externalizing behavior at age 3, more conceptual and language problems at age 4 and lower IQ at 4.5 years. In combination, the infants in Profiles 4 and 5 were more likely to have such medical risk factors as: abnormal head ultrasound reading, chronic neurological abnormalities, disease with risks to the brain and diagnosis of **cerebral palsy (CP)**, even when controlling for the influence of GA and **socioeconomic status (SES)**.<sup>5</sup> It is unlikely that the primary care physician would overlook or miss the need for close developmental follow up with risk factors such as GA. However, the NNNS also identified infants with neurobehavioral risks whose medical histories were noncontributory. Traditionally these infants would have a much higher probability of having these less obvious risk factors realized, representing missed opportunities for identification.

A recent study demonstrated that when pediatricians relied on their "**developmental impression**" (PDI) of an infant at 12 and 24 month office visits, they identified only 9.5% of preterm and 5.6% of

term infants who went on to qualify for early intervention services on the basis of developmental and/or behavioral disorders. This rate increased to 31% of preterm and 12.9% of term infants when a combination of PDI and a parent-report developmental questionnaire were utilized.<sup>3</sup> These findings raise the questions:

- 1) If those same infants were evaluated during their first month using a more sensitive instrument, might they begin intervention in their first year, with greater potential for successful outcome?
- 2) If so, what form might this early supportive intervention take, and what is the evidence that intervention so early in infancy is beneficial?

Early developmental support emphasizes "goodness of fit" between the infant, the caregiver and the environment,<sup>6</sup> and identification of elements of protection such as maternal education, maternal sensitivity and social support, as well as sources of risk. The goals of intervention with the infant are to optimize comfort, feeding, and sleep, conserve energy for growth and development, foster infant responsiveness, and promote engagement with the environment. When the "fit" between infant needs (or even preferences) and caregiving style is enhanced, routines become mutually pleasurable. Thus, strategies for intervention include engaging the infant and parent in positive interactions that have the potential to improve developmental and behavioral outcomes.

## INFANT INTERVENTIONS

One such strategy is nurturing touch. Early touch exerts an essential, profoundly positive influence on infant adaptation and maternal well-being.<sup>7</sup> Skin-to-skin holding, also termed **kangaroo care (KC)**, maintains thermal and physiologic regulation, enhances sleep, reduces reactivity to painful procedures such as heel-lance, and conserves energy

for growth and healing, not only for term infants, but for **low birth weight (LBW)** infants who require ventilatory support.<sup>8</sup> In a **randomized controlled trial (RCT)** of preterm infants, KC during hospitalization was associated with higher cognitive and motor scores on the Bayley Scales of Infant Development.<sup>9</sup> Additionally, KC for term and preterm infants can increase a mother's feeling of well-being, enhance maternal attachment with her infant, increase production of breastmilk, and offer a greater likelihood that breastfeeding will continue beyond the newborn period (which is also associated with higher IQ scores).<sup>10,11</sup> Thus, mothers are encouraged to hold their babies skin-to-skin as early as possible after delivery and frequently during early infancy.

Another touch-related intervention that has demonstrated value in early infancy is containment or "facilitated tucking", which has been shown through randomized trials to be a non-pharmaceutical intervention for procedural pain.<sup>12</sup> Pediatricians often encounter reluctance on the part of the parent to assist in holding their infant during blood draws, IV placement and injections. However, evidence in the pain literature supports parent participation as a comforting influence, particularly when a parent is holding the infant.<sup>13</sup>

Infant massage entails moderate touch pressure and slow, rhythmic stroking of the extremities, chest, abdomen, back and face. Parents are instructed not only in the technique, but to be mindful of the infant's behavioral and physiologic responses, and to modify their approach according to their infant's tolerance and preferences. For infants who are highly reactive or fragile, massage is incorporated gradually into their care.<sup>14</sup> RCT's with preterm infants have shown that the proprioceptive input, and range of motion inherent in infant massage have direct benefits for preterm infant bone mineralization. Moreover, massage has indirect effects in supporting infant weight gain, presumably by promoting sleep, digestion and appetite.<sup>15</sup>

In general term infants are thought to sleep better and to have less irritability when massage is part of their care routine; however, on systematic review, only weak evidence supports these claims.<sup>16</sup> Additional study is needed before infant mas-

sage can be widely recommended as a complementary intervention for infants with colic and fussiness. However, one could theorize that an intervention that provides moderate proprioceptive and tactile input in accordance with the infant's cues of receptivity would have the potential to promote overall relaxation and should be beneficial for any irritable infant, including infants with **Neonatal Abstinence Syndrome (NAS)**. In a randomized clinical trial (N=73), Lee and McNamara studied the effects of **developmental intervention (DI)** with and without infant **massage (M)**, administered by occupational therapists, on the dosing schedule for withdrawal of methadone-exposed infants.<sup>17</sup> They hypothesized that infant massage could promote relaxation, as well as overall neurobehavioral organization. For withdrawal symptoms, infants

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**“mothers are encouraged to hold their babies skin-to-skin as early as possible after delivery and frequently during early infancy.”**

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were treated initially with the standard pharmacologic intervention regimen of morphine with added phenobarbital. Once the patient's symptoms were captured the patients were randomized to receive either the research intervention of M plus DI or DI alone. Care providers were blinded to the interventions, which occurred in a secluded room for about 35 minutes once a day, 5 times a week. Weaning of morphine was carried out according to NAS scores. There were differences in outcomes between preterm and full term infants. Massage shortened the **length of stay (LOS)** for 35-36 week preterm infants (22±9 vs.30±17 days, P=0.003) but LOS did not differ with the addition of M among full term infants. All infants were tested at the same intervals with the NNNS. On the NNNS, massage improved attention for preterm and full term infants while DI alone did not.

Both M and DI decreased hypertonicity in full term infants.

The evidence is stronger for positive effects of infant massage on the interaction between infant and parent.<sup>16</sup> Benefits of infant massage for new mothers include lower rates of depression and anxiety, and greater sensitivity as caregivers.<sup>18</sup> Engagement in nurturing touch practices such as KC and infant massage can result in an infant-caregiver dyad that is more comfortable with giving and receiving touch, and with face-to-face interaction. Through these experiences, which parents often perceive as intensely pleasurable, caregivers may become more attuned to communicative facial expressions and behavioral cues of the infant – a powerful element in healthy attachment, and in social-emotional and language development.<sup>19</sup>

## **CHANGING TRENDS IN DEVELOPMENTAL SUPPORT IN RI**

During the hospital stay, maternal history often drives referrals for developmental intervention. Consistent with a traditional definition of risk, infants of mothers with high risk pregnancies, difficult deliveries, or prenatal substance abuse may be referred for in-hospital developmental assessment and support. These families also are more likely to be referred to early intervention at discharge. Increasingly, though, it is the infant's neurobehavioral presentation that drives the referral process. Infants for whom the range of states of arousal are limited, who are difficult to console, or appear tremulous or disorganized in their behavioral presentation are now more likely than before to be referred for additional neurobehavioral assessment and intervention. Among these are infants born to the increasing numbers of women taking **selective serotonin reuptake inhibitors (SSRIs)** who present with variations in sleep architecture and neurobehavioral performance, increasing the potential for developmental sequelae.<sup>19</sup> This trend in referral reflects a shift in our local understanding of development in RI, representing a lower threshold for differences in newborn behavior and development, and a broader definition of risk.

The Newborn Nurseries and NICU at **Women & Infants Hospital (WIH)** has used the NNNS since its inception in

1992. Initially the NNNS was used as a research instrument, but increasingly it is being utilized for the clinical assessment of newborns with a variety of presenting problems, including atypical feeding and/or disorganized behavior. As a clinical tool, the NNNS can be used to discern aspects of infant performance that may reflect current vulnerabilities and needs.<sup>20</sup> Like its predecessor, the NBAS, the NNNS is best administered with the parent(s) to highlight strengths as well as areas of concern. Parents are drawn into a discussion of modifications that they can make in the amount or type of stimulation during routine care to optimize the infant's comfort and responsiveness.

Current trends in infant referral for assessment also reflect an expanded view of what constitutes protection in the life of the child. For some parents, the transition to parenthood is laden with anxiety. These parents may appear detached, ambivalent, hyper-vigilant or depressed. During the NNNS assessment and subsequent touch-based interventions, efforts are made to help anxious parents recognize when their infant is responding positively to their approaches, or when the infant's behavior is communicating distress. When an infant's presentation is typical, the opportunity to see the range of competencies their infant possesses can be reassuring. Strategies for utilizing the infant's strengths to foster overall behavioral organization can be offered. This type of anticipatory guidance helps parents, especially first-time parents, to have more realistic expectations of their infants' behavior, and to derive mutual pleasure through early interaction with their infant.

Alternatively the NNNS assessment may reveal subtle signs and symptoms that can contribute to discovery of previously unrecognized risk factors; even prenatal substance exposure. During NNNS assessment, mothers are able to observe vulnerabilities of their infants, such as excessive startling, tremors or inconsolability. Mothers may become aware, for the first time, of the effects on their infant of medications or substances used during pregnancy. Once cognizant of these effects, it has been our observation that these mothers are sometimes more receptive to guidance in interacting with their infant, including instruction in providing nurturing touch in a way that is mutually rewarding, and has

the potential to strengthen early relationships.

When parents understand their infant's unique style of responding to the world, they are more likely to provide care that is sensitive to the infant's needs. Thus at WIH, the newborn developmental assessment, in and of itself, is being used as one of the earliest supportive interventions for infants at risk. Combined with early engagement in touch-based interaction, as a complementary, low cost treatment, these interventions have the potential to take at-risk dyads toward successful outcomes.

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# Newborn Hearing Assessment In 2010

Andrew P. McGrath, AuD, Betty Vohr, MD, Courtney A. O'Neil, AuD

In 1993 the Rhode Island General Assembly mandated universal newborn hearing screening (UHNS) and required third-party payment for screenings (RI Public Law 23-23-13). Rhode Island was the first state in the nation to do so. Today 45 states and territories have statutes related to UNHS. A large body of research supports the effectiveness of newborn hearing screening in detecting hearing loss at an early age and reducing the age at which children with hearing loss are enrolled in Early Intervention (EI) programs. Current challenges include improving post-diagnosis follow-up; ensuring timely enrollment in EI; appropriately and effectively referring for amplification; and monitoring for later-onset hearing loss.

## JUSTIFICATION FOR INFANT HEARING SCREENINGS

Failure to detect hearing loss in children may result in lifelong deficits in speech and language acquisition, poor academic performance, personal-social maladjustments, and emotional difficulties.<sup>1</sup> Neonatal hearing loss is one of the most commonly occurring birth defects with an incidence of 1.1 per 1000 live births, or some 12,000 to 16,000 babies each year in the United States.<sup>2,3</sup> As many as half of these infants have no risk factors for hearing loss; thus hearing loss may not be suspected until the child misses speech milestones. Prior to newborn screening, clinicians in the US did not diagnose hearing loss until an average age of 30 months,<sup>4</sup> by which time the child lagged behind his or her age-peers with respect to speech and language acquisition. In the US in 2007, 66.4% of infants were diagnosed with either normal hearing or hearing loss by age 3 months; in Rhode Island the rate was 93.3%.<sup>5</sup>

## RHODE ISLAND PROGRAMS

Following the passage of legislation mandating UNHS, the Rhode Island Hearing Assessment Program (RIHAP) was founded to oversee and coordinate the screening programs at the eight (now seven) birthing hospitals in the state. RIHAP continues to serve in this role, pro-

viding training, equipment, and technical support for each of these hospitals. As importantly, RIHAP maintains an extensive database of all the outcomes of statewide hearing screenings; coordinates follow-up testing for those who either failed their screening or are otherwise at risk for hearing loss; and facilitates the treatment of infants diagnosed with hearing loss.

RIHAP works with Early Intervention (EI) programs throughout the state, the Family Guidance Program at the RI School for the Deaf, and with audiologists throughout the region. Rather than being the focal point of the program, RIHAP serves as the conduit for children with hearing loss to enter the statewide program,<sup>6</sup> which operates under the oversight of the RI Department of Health and receives funding from state and federal grants as well as support from individual hospitals and treatment facilities.

## NATIONAL PROGRAMS

The Early Hearing Detection and Intervention (EHDI) Program of the Centers for Disease Control and Prevention (CDC) works with federal, national, and state agencies to develop newborn hearing screening programs in each state. As of 2010, 53 of 59 US States, Districts, and Territories have cooperative agreements with EDHI and receive funding and support through the program.<sup>7</sup> EHDI goals include the "1-3-6 plan," which calls for all infants to be screened by age one month, all children who do not pass the screening to receive diagnostic audiological testing by age three months, and all

children with confirmed hearing loss to be enrolled in an appropriate intervention program by the age of six months. Other goals include identification of later-onset hearing loss, coordination of EI with the primary care provider, tracking programs to minimize loss to follow-up, and comprehensive monitoring to assure that each state program is working efficiently to meet these goals.

Currently 45 U.S. states and territories have legislation regarding newborn hearing screening and 26 states have legislation which mandates universal newborn hearing screening. Twenty-nine states require reporting of hearing screening results to the Department of Health.<sup>4</sup> According to 2007 EHDI data, 45 of 47 states and territories reporting statistics for that year screened over 90% of newborns and 37 out of these 47 reporting entities screened over 95% of their infants.<sup>5</sup> Rhode Island consistently screens over 99% of newborns.

## BENEFITS OF NEWBORN HEARING SCREENING

Research into the efficacy of UNHS confirms that newborn hearing screening significantly speeds the diagnosis of hearing loss and initiation of intervention. In 2008 the US Preventive Services Task Force recommended routine screening of newborns for hearing loss based on strong evidence of the positive long-term benefits of early diagnosis.<sup>8</sup> Sininger et al. concluded that infants screened for hearing loss are diagnosed 24.6 months earlier, fit with amplification 23.5 months earlier,

Table 1: Hearing Screening: Comparison of RI to Totals for the 2007 EDHI Data

State / Territory	Rhode Island	Totals (n = 47)
Total Births	13,304	3,449,300
Died/Parents Declined Screening	136	15,523
Infants Eligible for Screening	13,168	3,433,777
Number of Infants Screened	13,123	3,345,629
Percent Screened	99.7 %	97.4 %
Number of Infants Not Screened	45	88,148
Percent Not Screened	0.3%	2.7%

[http://www.cdc.gov/ncbddd/ehdi/2007-data/2007\\_Screen\\_Web\\_Rev.pdf](http://www.cdc.gov/ncbddd/ehdi/2007-data/2007_Screen_Web_Rev.pdf)

**Table 2: Diagnosis of Hearing Loss:  
Comparison of RI to Totals for the 2007 EDHI Data**

State / Territory	Rhode Island	Totals (n = 44)
Total Screened	13,123	2,881,738
Total Not Passed	203	60,950
Total Normal Hearing	165	22,266
Total Normal Hearing <3 Mos Age	158	15,295
Total Hearing Loss	14	3,340
Total Hearing Loss < 3 MosAge	9	1,757
Total Diagnosed	179	25,696
Total Diagnosed < 3 MosAge	167	17,052
Percent Diagnosed < 3 Mos Age	93.3%	66.4%

[http://www.cdc.gov/ncbddd/ehdi/2007-data/Diag\\_2007\\_Age\\_Web\\_Rev.pdf](http://www.cdc.gov/ncbddd/ehdi/2007-data/Diag_2007_Age_Web_Rev.pdf)

and enrolled in EI 20.2 months earlier than infants who are not screened.<sup>9</sup> Vohr et al. reported in a RI cohort that participation in EI services by three months of age was associated with improved early language skills in children with hearing loss. Though children with moderate to profound hearing loss continued to have expressive and receptive language delays, the benefits of EI for all children with hearing loss were demonstrated.<sup>10</sup> Yoshinaga-Itano concluded that those children with hearing loss and no other disabilities, when identified early and appropriately treated, have the ability to develop normal language skills.<sup>11</sup>

Advances in cochlear implant technology and surgical techniques have coincided with the proliferation of UNHS programs. The net result of this confluence has been the implantation of ever-younger patients identified as profoundly hearing impaired shortly after birth. These procedures have been found to be both safe and efficacious in multiple studies.<sup>12,13</sup> Sharma et al. and Dorman et al. have shown that neural plasticity within the auditory system begins to decline after approximately 3.5

years of age and that earlier implantation tends to result in normal or near-normal central auditory function.<sup>14,15</sup> Similarly, Philips et al. determined that earlier screenings led to more successful outcomes among children who were diagnosed with profound hearing loss and promptly fitted with cochlear implants. They concluded that this earlier intervention resulted in improved auditory receptive skills and speech intelligibility.<sup>12</sup>

## Rhode Island consistently screens over 99% of newborns.

### UPDATES TO HEARING SCREENING PROGRAMS

The **Joint Committee on Infant Hearing (JCIH)**, a multi-agency task force concerned with the issues of childhood hearing loss, issued a position statement in 2007 with several revisions to their prior statement from 2000.<sup>3</sup> One significant change was the expansion of the defini-

tion of hearing loss to include hearing loss specific to the auditory nerve and to revise recommended screening protocols for infants at risk for these conditions. There is strong evidence that infants in the **neonatal intensive care unit (NICU)**, and specifically those with a history of hyperbilirubinemia, sepsis, and exposure to gentamicin, are at risk for damage to the eighth cranial nerve and/or auditory brainstem.<sup>16-18</sup> **Otoacoustic Emissions (OAE)** testing, which has traditionally been the initial screening tool of choice, measures the response of cochlear outer hair cells and thus may be normal even in the presence of retrocochlear dysfunction. To address these concerns, JCIH made new recommendations for the use of **automated auditory brainstem response (AABR)** screening in the NICU rather than OAE screening. Though generally more time consuming than OAE and somewhat less sensitive to mild hearing loss, the AABR is sensitive to dysfunction of the auditory nerve and thus will allow the hearing screening team to detect neural as well as cochlear hearing losses.

Other changes in JCIH recommendations include refinement of audiological and medical follow-up of infants with suspected hearing loss, specifications for EI programs, recommendations for data collection and management at the state level, and communication of hearing screening results to parents as soon as possible. Many states, including Rhode Island, have traditionally discussed only the results of failed screenings with parents, while passed screenings were recorded but not universally discussed with parents. Often even the fail results were communicated to the parents through the mail only after the newborn had been discharged from the hospital. These newest guidelines call for universal “results-to-parents” before discharge from the hospital.

**Table 3: Intervention/Referral to EI:  
Comparison of RI to Totals for the 2007 EDHI Data**

State / Territory	Rhode Island	Totals (n = 44)
Total Hearing Loss	14	3,364
Eligible for EI	10	2,539
Total Enrolled EI	10	1,792
Percent Enrolled in EI - <i>of those Eligible</i>	100%	70.5%
Percent Enrolled in EI - <i>of those w. Hearing Loss</i>	71.4%	53.3%
Enrolled EI - Before 6 Months	7	1,058
Percent Enrolled EI - Before 6 Months	70.0%	59.0%

[http://www.cdc.gov/ncbddd/ehdi/2007-data/2007\\_Enrolled\\_Part\\_C\\_EI\\_Web\\_Rev.pdf](http://www.cdc.gov/ncbddd/ehdi/2007-data/2007_Enrolled_Part_C_EI_Web_Rev.pdf)

### RECENT DEVELOPMENTS IN HEARING ASSESSMENT IN RHODE ISLAND

Hearing screening and diagnostic data for Rhode Island for 2007 are shown in Tables 1 and 2. Though RI has excellent rates of screening and low fail rates, the UNHS and EI programs in RI continue to adjust to meet national recommendations. In late 2009/early 2010 all of the birthing hospitals in Rhode Island started provid-

ing the results of all newborn hearing screenings to parents prior to discharge. Also in 2010 a new hearing screening protocol will be implemented in the NICU at Women & Infants Hospital. To address evidence-based concerns about neural hearing loss, initial screenings will be performed using AABR rather than OAE, following the recommendations of the JCIH.

Early Intervention data for Rhode Island are summarized in Table 3. EI programs remain a vital link in the care of children with hearing loss and other developmental challenges, providing services for children up to the age of three years. Though EI has suffered recent budget cuts, the program continues to meet federal requirements for the **Individuals with Disabilities Education Act (IDEA)** for infants, toddlers, and their families. Efforts are under way to ensure the uniformity of services across EI agencies and to coordinate these intervention services with primary care providers. Through focused “mentor groups,” EI ensures that at least one staff member in each facility receives specialized training to deal with children with autism, hearing loss and deafness, and other challenging conditions.

The Rhode Island Auditory-Oral Program opened in 2005 as a collaborative effort of the RI Department of Education, the Rhode Island School for the Deaf, participating school districts, and other organizations. This program offers specialized instruction for children who have hearing loss or are deaf to learn to listen and speak with the benefit of hearing aids or cochlear implants. The program caters to both preschool and school-aged children with classrooms including children with normal hearing and speech as well as those children with hearing loss or who are deaf. Professionals and family members work together at home and in the classroom to foster the skills necessary for receptive and expressive spoken language.

Finally, efforts are underway to improve the reporting of audiology data to the RI Department of Health. State law mandates the reporting of hearing loss identified before the age of five years; the JCIH recommends the reporting; and it is hugely important for coordination of care between audiologists, physicians, educators, and others charged with the stewardship of children with hearing loss.

The KIDSNET program has expanded to include hearing assessment data, and pediatric audiologists statewide are being trained to use this resource. At the same time, the program is being modified based on the observations and recommendations of these audiologists, with the goal of implementing a quick and comprehensive reporting mechanism and reference tool that can then help facilitate interventions.

## CONCLUSIONS

Rhode Island led the way toward universal newborn hearing screening 16 years ago and our state continues to be the vanguard of advancements. Research into long-term outcomes of infants diagnosed with hearing loss is ongoing, as is investigation of methods for reducing the number of children lost to follow-up. Over the next few years, individuals who were among the first generation of infants in the UNHS era will reach the age of majority, attend higher education, and enter the workforce. Only as these events unfold will we be able to gauge the true efficacy of our newborn hearing screening programs and their impact in Rhode Island.

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# Testing With Simulation Before a Big Move at Women & Infants Hospital

Jesse Bender, MD, Robin Shields, RNC, Karen Kennally, RN BSN

**Women & Infants Hospital, Rhode Island's** regional high risk maternal and neonatal referral center, opened the nation's largest single family room neonatal intensive care unit (NICU) in September 2009. Housed in the adjacent newly constructed South Pavilion, this 50,000 square foot 80-bed NICU features family-centered care. Parents, now able to stay at their baby's bedside 24 hours per day, can expect less stress than in the traditional chaotic NICU,<sup>1,2</sup> fewer catheter-related infections,<sup>3</sup> and improved neurodevelopmental outcomes with normalization of noise and light stimulation.<sup>4</sup>

## THE CHALLENGE

The prospect of transitioning from a 10,000 square foot open bay model (with prams, isolettes, and warmers clustered in six bays) to a unit 5 times larger with a single family room 'model of care' was daunting. Our system had evolved over decades with refinements from generations of caregivers. That system was built on processes that were efficient, with redundancies for patient safety. Now, over the course of months, new processes would need to promote that same level of patient care. For example, physicians in the older model could readily identify the pulse of the bay with a quick scan, and neighboring nurses easily shared responsibility for each other's patients. In the new unit, staff would function in single, twin and triplet rooms spread over two floors, the combined size of a football field. How would staff be alerted and respond to acute situations?

Multidisciplinary workflow committees formed to wrestle with many the changes and unknowns. Preemptive changes, both strategic and procedural, were implemented as far in advance as possible, such as enhanced nurse practitioner coverage and delivery phone usage. But many best practices were elusive without a full understanding of how systems would come together. Despite

all efforts, collective anxiety escalated as the move neared. We needed a "test flight."

TESTPILOT—Transportable Enhanced Simulation Technologies for Pre-Implementation Limited Operations Testing—was organized to see how individual systems could integrate into a new equivalently safe and effective NICU environment.

## PRIOR USE OF SIMULATION

The utilization of simulation training to test new medical facilities had already been successfully implemented. In fact, the TESTPILOT concept originated with the opening of the Rhode Island Hospital adult emergency room in 2005. *In situ* simulations of cardiac arrest, multiple trauma, septic shock and pediatric toxicology were run four days prior to opening, letting staff identify, and address, multiple operations issues.<sup>5</sup> A new hospital facility in Texas used similar simulation-based protocols to orient code blue teams in the months after opening. Twelve mock codes in various non-ICU locations were run, comparing perceived and actual response times for resuscitation interventions.<sup>6</sup>

Nevertheless, the scope and complexity of TESTPILOT-NICU were unprecedented. A functional intensive care unit was simulated prior to its opening. The aims were to assess translation of existing processes to the new NICU, to minimize patient exposure, to allow personnel from all shifts to explore the new NICU, and to integrate solutions into the orientation workshop for all NICU staff. We hypothesized that 1) despite years of meticulous planning, numerous process gaps would be discovered, and 2) participants would feel better prepared to work in the new environment as a result of these sessions. TESTPILOT-NICU was designed as an observational study with consent obtained prior to participation and videotaping.

## THE SCENARIOS

Nurses, respiratory therapists and physicians scripted scenarios, setting the stage with common situations such as management of prematurity, meconium aspiration syndrome (MAS) with pulmonary hypertension (PPHN), seizures in the large-for-gestational age (LGA) neonate, and hydrops with arrhythmias. (Table 1) Balanced assignments were



Figure 1: Vested TESTPILOT Participants (note SimNewB™ Mannequin<sup>7</sup>)

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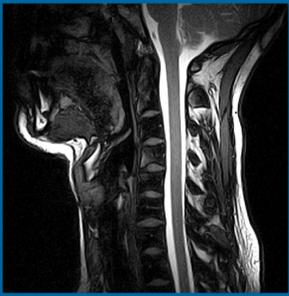
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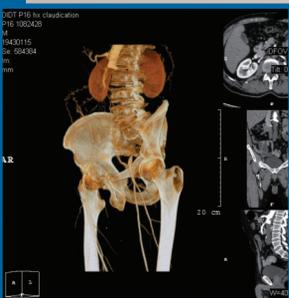
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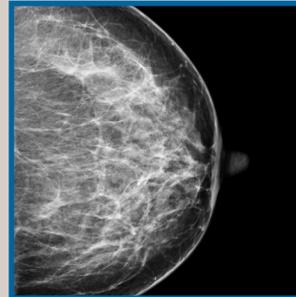


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**TABLE 1: Description of Scenarios**

PATIENT	1 <sup>st</sup> Scenario	2 <sup>nd</sup> Scenario
Angel	Premature 28 weeks, incoming transport Secure endotracheal tube, set up ventilator, chest film, surfactant	Place central lines, hang IV Fluids, write orders
Bobby	Resolved cardiac hydrops, no IV, hyperkalemia, stable arrhythmia, EKG	If meds arrive, hung, labs sent, PAC's resolve; otherwise progress
Cassius	Pulmonary hypertension, meconium aspiration; elective intubation, volatile SaO <sub>2</sub> , acidosis; stressed parent	Improves on oscillator, bolus hypotension, vasopressors, inhaled nitric oxide
Delila	Late preterm LGA; mom scared, seizure, persists despite dextrose, Phenobarbital	Serial desaturation, apnea, intubate, prepare for CT scan
Wildcard: Code Stork	Precipitous delivery of 26 week twins: twin A on high risk antepartum floor, then mom to OR for breech twin B	Twin room admission; two ventilators, X-rays, meds, lines, carts

built for each group of health care providers, orchestrated for baseline chaotic realism and infused with task-oriented urgency. (Figure 1)

Twenty minutes into each session, an additional scenario was introduced, to which existing staff would have to adjust. Some of these “wildcard” scenarios drew from previous experiences in the NICU, such as coordinating multiple transports, managing a power outage, or simultaneous Code Blues (now on separate floors). Other wildcards tested geographic concerns from the original building (Infant Rapid Response Team called

to the Newborn Nursery; an emergent delivery in Triage, or “slow to start” in the Labor & Delivery Room).

**THE TIMING**

Several scheduling trade-offs were made for the sessions. *In situ* simulation best tests integration, but if tested too soon individual systems may have been incompletely functioning. Adaptations were made for the evolving functionality of the bedside monitors, electronic medical record, and wireless communication devices. For example, until wireless communication devices were programmed to send

laboratory values directly to the provider, results were hand-delivered on pieces of paper. But scheduling the sessions too close to the actual move would also have been problematic. Ample lead time for identification of issues was required to fix problems and formulate a staff orientation plan. By using mannequins before the transition, we avoided putting actual neonates at risk. Thus, six sessions were offered 6 to 9 weeks prior to the transition.

**THE SETTING**

Participants were recruited from all shifts and specialties, enticed by the opportunity to explore the new NICU. One eighth of the new NICU was chosen for simulation (Figure 2), the rooms staged with familiar monitors, hybrid paper charts for orders, and an active electronic medical record for documentation. Simulation realism ranged from low to high fidelity using appropriate mannequins and equipment.

**THE SESSIONS AND DEBRIEFING**

Each session started with a 90-minute orientation to the facility, code alarms, the location of equipment, and the use of communication devices. Multidisciplinary groups of participants, appropriate to the demands of the scenario, settled into each room. The study facilitator “confederates” introduced assignments, and allowed participants to explore the vignette over a 30- minute



Figure 2. Schematic drawing of NICU, with focus of TESTPILOT shaded

simulation. This was followed by one hour of facilitated debriefing directed towards discovery of problem areas. Participants had a second 30-minute simulation, progressing with the same patient, followed by a second debriefing.

### THE ISSUES IDENTIFIED

The response to TESTPILOT was overwhelmingly positive. While half of the participants had never experienced simulation before, nearly everybody suspended disbelief and stated the high impact on their practice. Each session generated more volunteer confederates. Nurses (28), physicians (15), respiratory therapists (11), radiology and laboratory technicians (10), assistant nurse managers (9), neonatal nurse practitioners (7), secretaries (3), and other hospital staff participated. They were 97% female, ranged from 21 to 61 years of age and 1 to 35 years of NICU experience.

Participants were universally constructive in the debriefing process, identifying 172 discrete latent safety threats. Communication, organizational, facilities, ergonomic and technical safety threats were resolved by workflow modification or by practice change. Systems for recruiting bedside assistance were modeled; verbal and written communication processes were revised and tested. Workflow was modified for the admissions process, running codes, and mobilization of the delivery and rapid response teams. Significant facilities issues were identified, as were staffing and training concerns. Feedback from our "parents" highlighted instances of ineffective family-centered care, enabling scripting and process changes.

### THE PARTICIPANT FEEDBACK

Staff preparedness was assessed with a series of questionnaires; 1) after TESTPILOT, 2) after the 4-hour employee orientation workshop, and 3) after the transition to the new unit. Awareness of supply and equipment locations, communication and workflow patterns improved in the weeks prior to transition. TESTPILOT accelerated and enriched the natural history of discovery and improvement, having a ripple effect on numerous workflow committees. Participants felt equally prepared by TESTPILOT or the orientation work-

shop, which was developed largely via TESTPILOT discoveries. Though only half of staff reported sufficient orientation to provide effective care in the new facility prior to the big move, the majority reported, in one-on-one interviews, they felt comfortable within three weeks.

### SUMMARY

Simulation can identify process gaps prior to major institutional change. NICU staff found simulation very beneficial for facilities orientation; the majority of providers considered patient safety enhanced by scenario-based training. TESTPILOT identified problems that could not have been identified by committees. This information improved processes and was used to tailor staff training workshops, all of which led to better preparedness and patient safety. The impact has been recognized as so beneficial that we are now collaborating with the Rhode Island Hospital Medical Simulation Center to build a simulation facility at Women & Infants Hospital.

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# 35 Years of Neonatal Follow-up In Rhode Island

Betty Vohr, MD, Bonnie Stephens, MD, and Richard Tucker

**Advances in perinatal and neonatal medicine** including the use of antenatal steroids,<sup>1</sup> and magnesium sulfate,<sup>2</sup> more aggressive delivery room resuscitation, surfactant,<sup>3</sup> prophylactic indomethacin,<sup>4</sup> improved ventilatory techniques<sup>5</sup> and nutritional management<sup>6-8</sup> have significantly improved survival rates of preterm infants.<sup>9, 10</sup> These improvements have been most notable for infants born with **extremely low birth weight (ELBW < 1000 grams)** and at the limits of viability (22-24 weeks).<sup>11, 12</sup> This improvement in survival has resulted in an increasing prevalence of infants at risk for neurodevelopmental impairments and infants with special health care needs. In response, there has been an emergence of specialized follow-up care programs at tertiary care centers in the United States that provide enhanced transitional care and post-discharge care, and ongoing assessments. All fellowship training programs in Neonatology in the United States must have a follow-up program for training fellows that monitors the outcomes of **neonatal intensive care unit (NICU)** graduates.

## **VERY LOW BIRTH WEIGHT (VLBW) SURVIVORS IN RHODE ISLAND**

Data from **Women & Infants Hospital (WIH)** is consistent with increased survival of our smallest and most vulnerable infants. Infants considered at the limits of viability are born at 22 to 24 weeks of gestation. Although the Academy of Pediatrics does not recommend active resuscitation of infants at 22 weeks gestation, it is recommended that physicians consult with families to develop a plan about the level of intervention for infants born at 23 to 24 weeks. Figure 1 shows the increase in the number of live births and survivors for these most immature infants of 23 to 24 weeks gestation in Rhode Island from 1990 to 2007. In 1990 there were 16 live births of infants of 23-24 weeks gestation and 7 survivors. This number increased to 38 live births in 2007 and 20 survivors. Increasing numbers of infants are being discharged on monitors, oxygen, special formulas,

medications, and gastrostomy tube feeds. These infants with special health care needs and their families benefit from the support of staff knowledgeable about the needs of high risk infants.

The Neonatal Follow-up Program at Women and Infants has been providing supplemental care to high risk infants since 1974. Initially infants seen in the Follow-up Program had been cared for in a 20-bed Special Care Nursery at the old Providence Lying-In Hospital. In 1984 the NICU was expanded to 41 beds when the hospital moved to its current site at 101 Dudley Street. Since that time the number of infants born at WIH and cared for in the NICU has increased, with a current daily census of almost 70 being cared for in the new 80-bed single room NICU. The mission of the Follow-up Program is to provide a continuum of specialized clinical care for graduates of the NICU, to monitor specific quality indicators, and to conduct prospective, longitudinal outcome studies including descriptive studies, interventional studies, as well as local and multicenter clinical trials.

## **CRITERIA FOR FOLLOW-UP AT WOMEN & INFANTS HOSPITAL**

Infants routinely scheduled for follow-up include premature infants weighing less than 1500 grams at birth, infants of any birth weight with neonatal compli-

cations that place them at developmental risk including **intraventricular hemorrhage (IVH)**, **bronchopulmonary dysplasia (BPD)**, **periventricular leukomalacia (PVL)**, asphyxia, meningitis, congenital malformations and infants discharged on cardiorespiratory monitors or oxygen. Definitions of subgroups of high risk infants seen are shown in Table 1.

The number of visits per year has increased from approximately 200 in 1974 to over 1268 in 2009, and the number of staff has increased from 3 (physician, psychologist, and nurse) to 17 (4 pediatricians including a medical director, 2 psychologists, nurse practitioner, a social worker, a **Rhode Island Parent Information Network (RIPIN)** parent consultant, an occupational therapist, a pulmonologist, 2 nutritionists, a manager, a business representative, a chart coordinator, and a data analyst). Staff provide comprehensive multidisciplinary assessments.

## **Referral Process**

Infants are primarily referred to the Follow-up Program from the NICU. In addition, **Early Intervention (EI)**, primary care providers, visiting nurses and parents may refer for growth, neurologic, developmental or behavioral concerns. Visits are scheduled from birth to adolescence, as indicated. High risk NICU graduates who move to Rhode Island from other parts of

**TABLE 1. Common Definitions of Patients Seen in Neonatal Follow-up Program**

**Premature** - any neonate born before 37 completed weeks of gestation. (37 weeks or less.)

**Low birth weight (LBW)** - birth weight less than 2500 g

**Very low birth weight (VLBW)** - birth weight less than 1500 g.

**Extremely low birth weight (ELBW)** - birth weight less than 1000 g.

**Micro premie** - any neonate whose birth weight is less than 750 g.

**Chronological Age** - The age of the infant based on the number of weeks or months since the actual date of delivery.

**Corrected Age** - The age of the infant calculated from the expected date of delivery. It may also be calculated by subtracting the number of weeks of prematurity from the chronological age. For example, an infant born 6 months ago with a gestational age of 28 weeks (3 months premature) has a chronologic age of 6 months and a corrected age of 3 months.

**Small for gestation** - weight <10<sup>th</sup> % for gestation

**Threshold of viability** - 22-24 weeks gestation

the country may also be referred for specialized follow-up. Informed consent for study involvement is obtained when indicated.

### Age of Assessment

For premature infants born prior to 34 weeks gestation, corrected age (time since mother's expected date of delivery) is used for assessments of growth, development and nutrition in the first 30 months of life. Chronologic age (time since birth) is used thereafter. In contrast, immunization schedules are always based on chronologic age regardless of gestational age at birth. Infants with special health care needs (such as home oxygen or apnea monitor, feeding issues, or neurologic injury/illness) are seen within 1 month of discharge and followed closely thereafter. Stable VLBW infants are seen for standard visits at the corrected ages of 3, 7 and 18 months, and then at the chronological ages of 30 months and 5 years. School age assessments are also completed on children who are participating in long-term studies or special programs. For example, adolescents in the Indomethacin IVH Prevention Trial are currently being assessed at 16 and 18 years of age.

### Type of Assessments

The Follow-up Clinic provides medical management for graduates of the NICU. Infants with medical problems such as apnea of prematurity, obstructive apnea, BPD, reflux and failure to thrive, are managed longitudinally until the problem is resolved or well controlled. Infants with more complex medical issues are referred to specialty clinics.

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**The number of visits per year has increased from approximately 200 in 1974 to over 1268 in 2009...**

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### Growth

Both appropriate-for-gestational age and small-for-gestational age VLBW infants are at increased risk of growth failure post discharge. Weight, length and head circumference are routinely collected longitudinally. Input is provided by the

staff nutritionists and recommendations made to the family and primary provider. Infants with significant growth failure are referred on for further assessment and possible candidacy for growth hormone.

### NEURODEVELOPMENTAL OUTCOMES

Premature infants are at increased risk of cerebral palsy (CP), hearing loss, vision impairments, developmental delays, cognitive impairments and learning problems. Early identification is imperative so that appropriate referrals can be made to support the optimal development of these children.

Rates of CP in ELBW infants in RI range from 9-12%. The most common form of CP in this population is spastic diplegia, accounting for 40% to 50% of all cases, followed by spastic quadriplegia, and hemiplegia. Although CP is the most well known and potentially most disabling motor abnormality associated with prematurity, preterm infants more often have less severe differences in their neurologic development including difficulties with fine and gross motor coordination. During the first year of life transient findings of abnormal tone and movement are common in the motor development of VLBW infants. Infants with suspect or abnormal neurologic findings benefit from EI services.

While much less common than motor disabilities, rates of neurosensory disabilities are higher in ELBW infants than the general population. Unilateral or bilateral blindness rates in Rhode Island are usually about 1% of ELBW infants. Milder visual impairments including myopia, strabismus, and lack of stereopsis (depth perception) occur more frequently. Hearing impairment benefiting from amplification occurs in about 1-3 % of VLBW infants.

The most common impairment seen in VLBW and ELBW infants at 18 and 30 months is cognitive impairment, defined as scores that are more than 2 standard deviations below the mean on standardized cognitive testing. At school age 50% of former VLBW children will need some type of resource or special education supports.

The Follow-Up Program provides neurodevelopmental assessments and management. Neurosensory, neuromotor, behavior, and developmental assessments are completed on all infants at each visit. Developmental assessments include the follow-

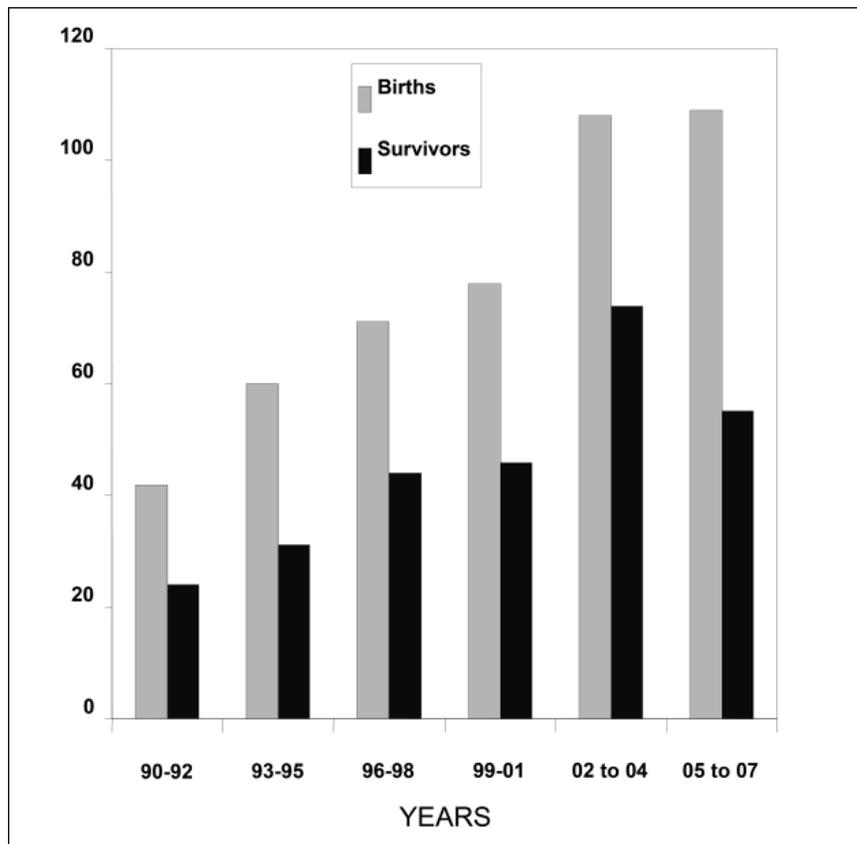


Figure 1. Number of live births and surviving 23 to 24 week gestation infants at Women & Infants Hospital by birth cohort.

ing: Cognitive, Language (Receptive and Expressive), Gross Motor, Fine Motor, Behavior (Internalizing and Externalizing and Adaptive Behavior), Executive Functioning, Memory, Achievement and Phonological Processing. Referrals are made to EI and the Department of Education as needed.

### Feedback

Results with recommendations are provided to parents at the end of each follow-up visit. A summary letter with findings and recommendations for appropriate supplemental support services including specialty services and early intervention within the community is sent to the primary provider.

### Teaching

The Follow-up Clinic is heavily committed to teaching fellows, residents, and medical students. In addition, visiting nurse practitioner students, fellows and physicians from other institutions and countries spend time in the clinic.

### Data Base

The Neonatal Follow-up Program maintains a comprehensive data base of neonatal characteristics, neonatal outcomes, and post-discharge outcomes. This data is used for in-house monitoring of outcomes and is a quality indicator for management in the NICU. Long term outcomes are considered important because of a known disconnect between neonatal outcome and post-discharge outcome.<sup>13,14</sup> The most demonstrative example of this was the use of high doses of ambient oxygen in the management of respiratory distress which through long term follow-up studies was associated with the subsequent diagnosis of retinopathy of prematurity with significant vision impairment or blindness.<sup>15,16</sup> The program has both data entry staff for collection of neonatal and follow-up data, and a data analyst.

### Transition Home Care

In 2006-2007 with the support of March of Dimes, CVS Charitable Trust, and the Department of Pediatrics, the Follow-up Program expanded services to provide comprehensive health integration services for infants considered at highest risk. The primary objective was to provide enhanced parent education, seamless support, and specialized infant services closely linked to the medical home (primary provider) during the first 6 months after discharge.

Nationally, 50% of ELBW infants are rehospitalized by 18 months of age. The objective of the enhanced services was to achieve fewer rehospitalizations and improve outcomes. Data collected from 2007 to 2008 indicate a significant decrease in the number of infants rehospitalized.

In summary, the Women & Infants Neonatal Follow-up Program plays an important clinical role to guarantee that all VLBW and high risk NICU graduates receive appropriate transition care, assessment and referral for community services as needed after discharge. In addition, ongoing surveillance of annual neonatal and post-discharge outcomes of high risk infants within an ever changing NICU environment permits the systematic monitoring of quality indicators and an audit of NICU interventions. In a 2004 publication comparing neurodevelopmental outcomes or death of ELBW infants cared for in the 12 centers of the NICHD Neonatal Research Network, our NICU had the lowest rates of cerebral palsy and the lowest combined outcome of any neurodevelopmental impairment or death.<sup>17</sup> Data such as these provide the evidence for changes and innovations in management that result in the continual improvement in acute NICU care, survival of premature infants, and in long term outcomes for Rhode Island's NICU graduates.

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# A Brief History of Neonatal Jaundice

William Cashore, MD

The authors of late 19<sup>th</sup> Century pediatric texts recognized *Icterus neonatorum* as a common finding in newborns. This condition was generally benign and self-limited. Since most newborns at the time were breast-fed, comparisons of the frequency of jaundice in breast and formula-fed infants were not immediately evident to medical observers until later, when formula-feeding was introduced in a larger and growing percentage of newborns (eventually, a majority). The first volume (1885-1891) of medical records from the original Providence Lying-in Hospital contains several observations of neonatal icterus, usually during the first week of what was then a 10-14 day length of stay.

*Icterus gravis* was also recognized as a more severe form of neonatal jaundice, often associated with profound anemia, abnormal neurological findings, and death. The cause of icterus gravis as an alloimmune hemolytic disorder was not recognized until years later when the immunology of human blood groups was elucidated. High parity rates led to recurrences within families, and recurrence rates after a first affected infant led clinicians to suspect a genetic basis for icterus gravis. The discovery of the Rh group of red cell antigens in 1940 confirmed the risk of recurrence within families.

Clinical research on hemolytic disease of the newborn in the 1940s and 1950s led to a better understanding of its pathogenesis and advances in its treatment. Increased understanding of the pathogenesis, diagnosis, and treatment of hemolytic disease contributed to advances in the whole field of perinatal and neonatal care. These advances included the development of systems for maternal screening which now includes prenatal diagnosis by maternal serology and amniocentesis. The early detection of hemolytic disease prenatally has led to invasive antenatal treatment by intrauterine fetal transfusion.<sup>1</sup> Not only have these advances led to antenatal interventions but they have improved the postnatal protocols for the management of neonatal Rh hemolytic disease, including close hematologic and biochemical monitoring of affected newborns and the invention of exchange transfusion<sup>2</sup> to correct anemia and to reduce and moderate bi-

lirubin levels. The neonatal protocols for Rh erythroblastosis were in turn closely linked to the early development of neonatal intensive care, since many Rh-affected newborns were delivered prematurely and with respiratory distress.

Certain pediatricians of the 1940s-1960s incorporated the care of infants with Rh erythroblastosis into their practice, forming teams of consultants to monitor affected newborns and carry out the tedious procedure of exchange transfusion when indicated. In Providence, these included John Barrett, MD, Frank Giunta, MD, Edwin Forman, MD, and several others, many of whom had received special postgraduate training in Rh disease from specialists in the disorder at large academic centers such as the University of Pennsylvania and the Boston Lying-in Hospital. Some general pediatricians who learned to specialize in Rh disease management continued their careers in the newborn nursery, educating themselves and their close colleagues as the first generation of neonatal intensive care specialists.

The high birth rates and multiparity typical of the post war Baby Boom years resulted in thousands of cases of neonatal disease in this country and abroad. Development of Rh – immune antiglobulin in 1968<sup>3</sup> coincided with a contemporaneous fall in birth rates during the 1970s and thereafter, so that with screening, immunoglobulin prophylaxis during pregnancy, and smaller family size, neonatal Rh erythroblastosis has now become rare.

Lessons learned from the study and treatment of Rh disease have carried over into a more detailed understanding of the causes and consequences of non-hemolytic neonatal jaundice. Subcortical central nervous system injury, or kernicterus, can occur with extreme elevations of unconjugated bilirubin even without alloimmune mediated hemolysis. A small proportion of newborns either overproduce bilirubin or fail to conjugate and excrete it in their first few days or weeks, with early bilirubin levels at risk of exceeding 20 or even 25 mg/dl. These babies need to be monitored and some need to be treated postnatally, to avoid exposure to unconjugated bilirubin levels far in excess

of the normal range, and potentially toxic. Conditions contributing to increased risk of, or from, hyperbilirubinemia include:

1. Prematurity, less than 37 weeks gestation
2. Breast feeding, with elevated bilirubin in 10-15% of breast fed newborns
3. ABO incompatibility, a cause of early hyperbilirubinemia in 1-2% of infants
4. G6-PD deficiency, whose frequency is unknown in the absence of a reliable neonatal screen

Because these and several other risk conditions have been associated with case reports of extreme bilirubin elevations and occasional kernicterus, early screening of all newborns for early or persistent jaundice is recommended.<sup>4</sup> Visible jaundice on Day 1 or early on Day 2 should prompt a laboratory determination of total and direct bilirubin concentration. A rate of increase > 0.25 mg/dl/hr should be followed with repeat determinations until stable or responding to ordered treatment. This rate of increase approximates to daily bilirubin levels > 5-6 mg/dl on Day 1, > 10-12 mg/dl on Day 2, or > 17-18 mg/dl on Day 3. Infants with bilirubin levels > 20mg/dl should be treated with high intensity light from multiple sources, positioned to expose most of the skin. Those with levels of 25 mg/dl or higher should be treated aggressively with frequent re-samplings in centers with the ability to potentially provide exchange transfusions. The bilirubin levels treated with effective doses of phototherapy should decline to acceptable levels within 12-24 hours. Most recently the American Academy of Pediatrics recommended treatment of hyperbilirubinemia based on hour specific nomogram findings of Vinod Bhutani et al.<sup>4,5</sup>

Infants with rising bilirubin levels in the nursery, close to but not exceeding the high risk guidelines, should be followed as outpatients within 1-3 working days of hospital discharge.<sup>5</sup> Follow up should include a weight check and feeding history, a detailed inspection for the extent and

intensity of jaundice, and if needed a follow-up bilirubin determination as indicated by the history and exam.

Since the 1980s phototherapy has superseded exchange transfusion as the treatment of choice for non-hemolytic hyperbilirubinemia.<sup>6,7</sup> (Phototherapy is helpful in cases of hemolytic hyperbilirubinemia, but may not be sufficient to correct the anemia or control the jaundice). Guidelines for both phototherapy and exchange transfusion, now a rare procedure, may be found in standard pediatric and neonatal texts, manuals for newborn care from various academic centers, and practice guidelines from the American Academy of Pediatrics.

### CONCLUSION

Hyperbilirubinemia is a universal problem in newborn nurseries, increasing in North America as rates of breast feeding and

borderline prematurity have increased in recent years. Neonatal jaundice is the most common reason to order laboratory tests in an otherwise well newborn. Although self-limited and benign in most cases, neglected or untreated severe hyperbilirubinemia can have dire neurodevelopmental consequences for the newborn.

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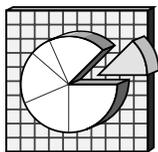
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## Health By Numbers

RHODE ISLAND DEPARTMENT OF HEALTH • DAVID GIFFORD, MD, MPH, DIRECTOR OF HEALTH

EDITED BY SAMARA VINER-BROWN, MS

# Health Status and Health Care Utilization Among Children In Rhode Island, 2007: Comparing Children With Public Insurance and Children With Private Insurance

*Hyun (Hanna) Kim, PhD, and Samara Viner-Brown, MS*

**Health status and health care utilization among children are** profoundly influenced by health insurance coverage. Uninsured and underinsured children are less likely than adequately insured children to receive preventive health care, have a usual source of care, and receive health care within a medical home that addresses their comprehensive needs. Gaps in health insurance coverage may lead to delayed or unmet health care needs among children.<sup>1</sup>

This report describes 1) the distribution of health insurance type among Rhode Island children, and 2) the health status and health care utilization disparities between children with public health insurance and children with private health insurance.

### METHODS

Data from the 2007 National Survey of Children's Health (NSCH-2007) were analyzed. The NSCH-2007, a random digit

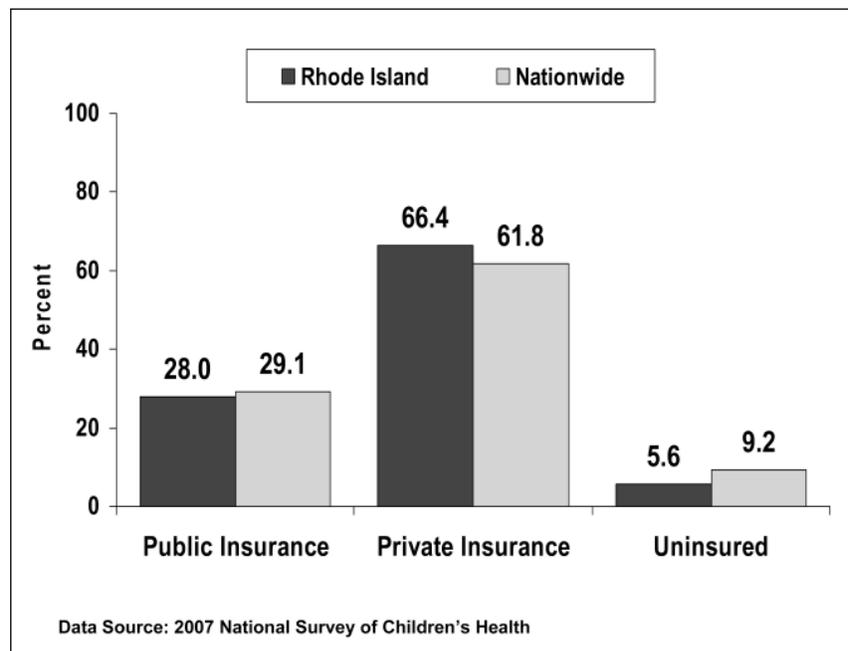


Figure 1. Distribution of Health Insurance Type Children 0-17 Years of Age, Rhode Island vs. United States, 2007

dial telephone survey conducted by the **National Center for Health Statistics (NCHS)**, was designed to produce national and state-specific prevalence estimates for a variety of physical, emotional, and behavioral health of children, and their health care access and utilization. The respondent was a parent or guardian of children younger than 18 years of age. In Rhode Island, the interviews were completed for 1,756 children with an overall response rate of 48.2%.<sup>2</sup>

Type of health insurance was determined using two survey questions: 1) Does the child have any kind of health care coverage, including HMOs or government plans such as Medicaid? and 2) Is that coverage Medicaid or the **State Children's Health Insurance Program (S-CHIP)** (known as **RItE Care**)? If a respondent said no to the first question, the child was classified as uninsured. If a respondent answered yes to both questions, the child was classified as having public insurance. If a respondent said yes to the first question and no to the second question, the child was classified as having private insurance.

Health status and health care utilization were assessed using various indicators from the survey, including health and functional status, health care access and utilization, and medical home.<sup>3</sup> Each indicator was examined by health insurance type to determine whether there were disparities between children with public insurance and children with private insurance. Uninsured children were excluded from the comparison due to the small sample size. Percentages presented here are weighted to represent all children 0-17 years of age in Rhode Island.

## RESULTS

### Distribution of Health Insurance Type

In 2007, 28% of Rhode Island children 0-17 years of age had public insurance, 66.4% had private insurance, and 5.6% had no insurance at the time of the survey. (Figure 1) The proportion of uninsured children in Rhode Island was lower than the national rate (9.2%), and the rate of private insurance was higher than the national rate (61.8%).

The percentage of children having public insurance was significantly higher among non-Hispanic black children (55.6%), Hispanic children (58.0%), children whose mother had less than high school education (73.8%), children living in households with incomes less than 100% of **Federal Poverty Level (FPL)** (78.0%), children living in a single mother household (63.9%), Hispanic children living in households where their primary language is Spanish (67.4%), and children with special health care needs (38.2%), compared to their counterparts. (Table 1)

### HEALTH STATUS AND HEALTH CARE UTILIZATION Health Status

Children with public health insurance were less likely than children with private health insurance to have very good/excellent general health (73.7% vs. 92.8%) and very good/excellent oral health (67.6% vs. 84.8%). Compared to children with private health in-

	% Public Insurance (n = 364)	% Private Insurance (n = 1,277)	% Currently Uninsured (n = 91)	P-value
<b>Overall</b>	<b>28.0</b>	<b>66.4</b>	<b>5.6</b>	
<b>Child Age</b>				
0-5	29.1	63.8	7.0*	0.4132
6-11	28.6	67.7	3.7	
12-17	26.4	67.4	6.2	
<b>Gender</b>				
Male	29.7	64.8	5.5	0.5898
Female	26.3	67.9	5.8	
<b>Race/Ethnicity</b>				
White, non-Hispanic	16.5	80.1	3.4	<0.001
Black, non-Hispanic	55.6	33.6	10.8*	
Hispanic	58.0	31.6	10.5	
<b>Mother's Education</b>				
< High School	73.8	17.9	8.2*	<0.001
High School	42.8	49.5	7.7*	
> High School	13.3	82.6	4.2	
<b>Household Income</b>				
0-99% FPL	78.0	10.7*	11.3*	<0.001
100-199% FPL	53.6	39.9	6.5	
200-399% FPL	13.8	82.6	3.6	
400% FPL or higher	3.2	92.6	4.2	
<b>Family Structure</b>				
Two-parent (biological/adoptive)	16.7	77.9	5.4	<0.001
Two-parent (at least one step-parent)	29.5	68.2	2.3*	
Mother only (no father present)	63.9	29.4	6.7*	
<b>Primary Household Language</b>				
Hispanic, Spanish Language	67.4	19.7	13.0*	<0.001
Hispanic, English Language	46.7	45.7	7.5*	
Non-Hispanic Children	21.3	74.4	4.2	
<b>Special Health Care Needs (SHCN)</b>				
Children without SHCN	25.4	68.4	6.2	0.0096
Children with SHCN	38.2	58.4	3.4*	

Data Source: 2007 National Survey of Children's Health  
 + FPL: Federal Poverty Level  
 \* Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

Table 1. Distribution of Health Insurance Type by Selected Characteristics

surance, children with public health insurance were more likely to be obese (21.4% vs. 11.3%), to miss 11 or more days of school in past year due to illness (9.4% vs. 3.9%), and to consistently exhibit problematic social behaviors (19.7% vs. 5.7%). (Table 2)

### Health Care Access and Utilization

Most children in Rhode Island had one or more preventive medical visits in the past year (96.2% for publicly-insured children and 98.8% for privately-insured children) and had a usual source for well and sick care (93.7% for publicly-insured children and 98.3% for privately-insured children). However, fewer children received care within a medical home (49.5% for publicly-insured children and 70.8% for privately-insured children). Children with public insurance were more likely to have unmet needs for care in the past year (10.8% vs. 2.7%). (Table 2)

### Adequacy of Insurance

Children with public insurance were more likely than children with private insurance to have health care coverage that usually or always meets insurance adequacy criteria (86.9% vs. 76.2%). The adequacy criteria include whether benefits meet child's needs, whether coverage allows the child to see needed providers, and whether out-of-pocket expenses are reasonable. However, children with public insurance were more likely to have gaps in insurance coverage during the previous 12 months than children with private insurance (9.7% vs. 3.6%). (Table 2)

**Table 2. Selected Indicators of Health Status and Health Care Utilization By Insurance Type: Children 0-17 Years of Age, Rhode Island, 2007**

Selected Indicators	Public Insurance % (95% CI*)	Private Insurance % (95% CI*)
<b>Health Status</b>		
Children whose general health is very good or excellent	73.7 (67.4-80.1)	92.8 (90.7-95.0)
Children age 1-17 whose oral health is very good or excellent	67.6 (60.8-74.3)	84.8 (81.7-87.8)
Children age 10-17 who are obese (BMI-for-age $\geq$ 95th percentile)	21.4 (13.3-29.5)	11.3 (7.9-14.8)
Children age 6-17 who missed 11 or more school days due to illness or injury during the previous 12 months	9.4 (4.0-14.7)	3.9 (2.6-5.3)
Children age 6-17 who consistently exhibit problematic social behaviors	19.7 (12.6-26.8)	5.7 (3.5-7.9)
<b>Health Care Access and Utilization</b>		
Children who had one or more preventive medical visit(s) during the previous 12 months	96.2 (93.6-98.9)	98.8 (97.7-99.8)
Children who have a usual source for well and sick care	93.7 (89.9-97.4)	98.3 (97.3-99.4)
Children with a medical home: health care that is continuous, coordinated, accessible, comprehensive, family-centered, compassionate, and culturally sensitive	49.5 (42.1-56.8)	70.8 (67.4-74.3)
Children with unmet need(s) for medical, dental, mental health or other health care during the previous 12 months	10.8 (6.5-15.2)	2.7 (1.6-3.8)
<b>Adequacy of Insurance</b>		
Children whose coverage usually or always meet insurance adequacy criteria: child's needs are met, child is allowed to see needed providers, out-of-pocket costs are reasonable	86.9 (82.4-91.3)	76.2 (73.0-79.5)
Children who had gaps in insurance coverage during the previous 12 months	9.7 (6.2-14.9)	3.6 (2.3-5.6)
* CI: Confidence Interval Source: Child and Adolescent Health Measurement Initiative. 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved from www.nschdata.org		

## DISCUSSION

The results point to substantial disparities between children with public insurance and children with private insurance in health status and health care utilization. In general, children with private insurance exhibited better health status and better health care access and utilization. However, those disparities might be due, in part, to the socio-economic and environmental differences because minority children, children with special health care needs, and children from low-income and single mother families were more likely to be covered by public insurance. Although public insurance was more affordable and adequate than private insurance, children covered by public insurance were more likely to have gaps in health insurance coverage, which might lead to lack of a medical home and unmet needs for care. These disparities should be interpreted as disparities in parents' perceptions, behaviors, and experiences and not as the disparities in the quality or effectiveness of the insurance.

*Note:* Parts of this article were originally presented to the Medicaid Evaluation Studies Workgroup in the Rhode Island Department of Human Services, October 29, 2009.

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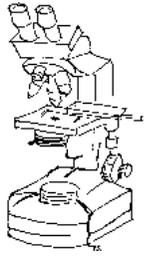
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# The Creative Clinician

## Complete Atrioventricular Block Due To Lyme Reinfection In a Six Year-Old Boy

Elizabeth Maria Goldberg, MD, and Kathleen M. Rotondo, MD

**Lyme borreliosis results** from infection by the spirochete *Borrelia burgdorferi*. The *Ixodes scapularis* tick, commonly known as the deer tick, acts as a vector and is endemic in coastal New England and the Mid-Atlantic States. The disease is divided into early (after 3-32 days incubation) and late stages, as well as limited and disseminated disease. Limited disease is manifest by erythema migrans, whereas disseminated disease may have cardiac and neurologic involvement.<sup>1</sup> Common presenting symptoms in children include fever, headache, erythema migrans (15% of cases), arthritis, arthralgia, myalgia, cranial nerve palsies, and meningitis. Carditis is present in only 0.5% of children.<sup>2</sup> We present the case of a six-year-old boy with early disseminated Lyme disease manifesting as complete atrioventricular (AV) block after presentation to the emergency department for a complaint of abdominal pain.

### CASE REPORT

A 6-year-old previously healthy boy presented to the emergency department [ED] of a hospital with a complaint of right lower quadrant abdominal pain. The pain was present on awakening seven hours prior to arrival to the ED. It was worse with movement, and mild in severity. There was decreased solid intake, but he had been drinking well. According to his parents, he was his normal playful self. The patient denied any nausea, vomiting, or loss of appetite. The medical history was significant for two previous episodes of Lyme disease. The first was at age four; the second was 18 months before presentation. Both episodes were diagnosed by erythema migrans and confirmed by Lyme serum studies. The patient was treated with amoxicillin both times and subsequent titers were negative. Immunizations were up-to-date. He had no known drug allergies and was not taking medications. His family history was negative for congenital heart disease, arrhythmias, and sudden death. Review of systems was significant for no recent tick bites, rashes, or fever. The patient denied cough, shortness of breath, and chest pain.

Physical examination revealed a well-developed boy in no apparent distress. He had a temperature of 37.2°C, blood pressure of 114/50mmHg, heart rate of 55bpm, respiratory rate of 16 respirations per minute, and oxygen saturation of 96% in room air. Height was 118.1cm (25-50th percentile) and weight was 23.6kg (50-75th percentile). Head and neck exam revealed moist mucus membranes and pupils that were equal and reactive to light. Lungs were clear to auscultation. Cardiovascular exam revealed bradycardia, a split S2 with a grade II/VI systolic ejection murmur heard best over the left

sternal border, and a grade I/VI short diastolic rumble at the apex. His abdominal exam revealed a liver edge 3cm below the right costal margin, no palpable spleen tip, no tenderness, and a negative "hop test". There was no peripheral edema; capillary refill was brisk, and peripheral pulses were palpable. Skin exam revealed no rashes.

Two hours after arrival the heart rate was 48bpm with no change in other vital signs. Complete AV block was recognized on EKG and the patient was transferred to a monitored bed in the pediatric intensive care unit. Zoll pads were placed; serum Lyme studies were ordered; a chest radiograph was performed, and the patient was started on intravenous ceftriaxone 2 grams daily (100mg/kg/day) for treatment of presumptive Lyme reinfection. A diagnosis of congenital heart block was also considered, given the absence of any prior cardiology workup. The differential also included myocarditis due to other infectious agents.

Chest radiograph, complete blood count, and electrolytes were all within normal limits. EKG revealed third degree heart block with a junctional escape rhythm, atrial rate of 90 and ventricular rate of 40. (Figure 1) Echocardiogram revealed normal left ventricular systolic function with trace mitral regurgitation and mild tricuspid regurgitation.

The patient's hospital course was significant for persistent bradycardia ranging from thirties to fifties without any symptomatology. Serial EKGs were performed on the first day and revealed fluctuating AV block. (Table 1)

**Table 1. EKG rhythm as recorded during hospital course and follow-up**

Days after presentation	EKG rhythm
1	Complete heart block with periods of 2:1 AV block
2	Occasional 1:1 AV conduction
3	Normal sinus rhythm with first degree AV block and frequent Wenkebach
5	Sinus bradycardia with first degree AV block and intermittent Type I second degree (Wenckebach) AV block
10	Sinus rhythm with borderline intermittent first degree AV block
30	Sinus rhythm

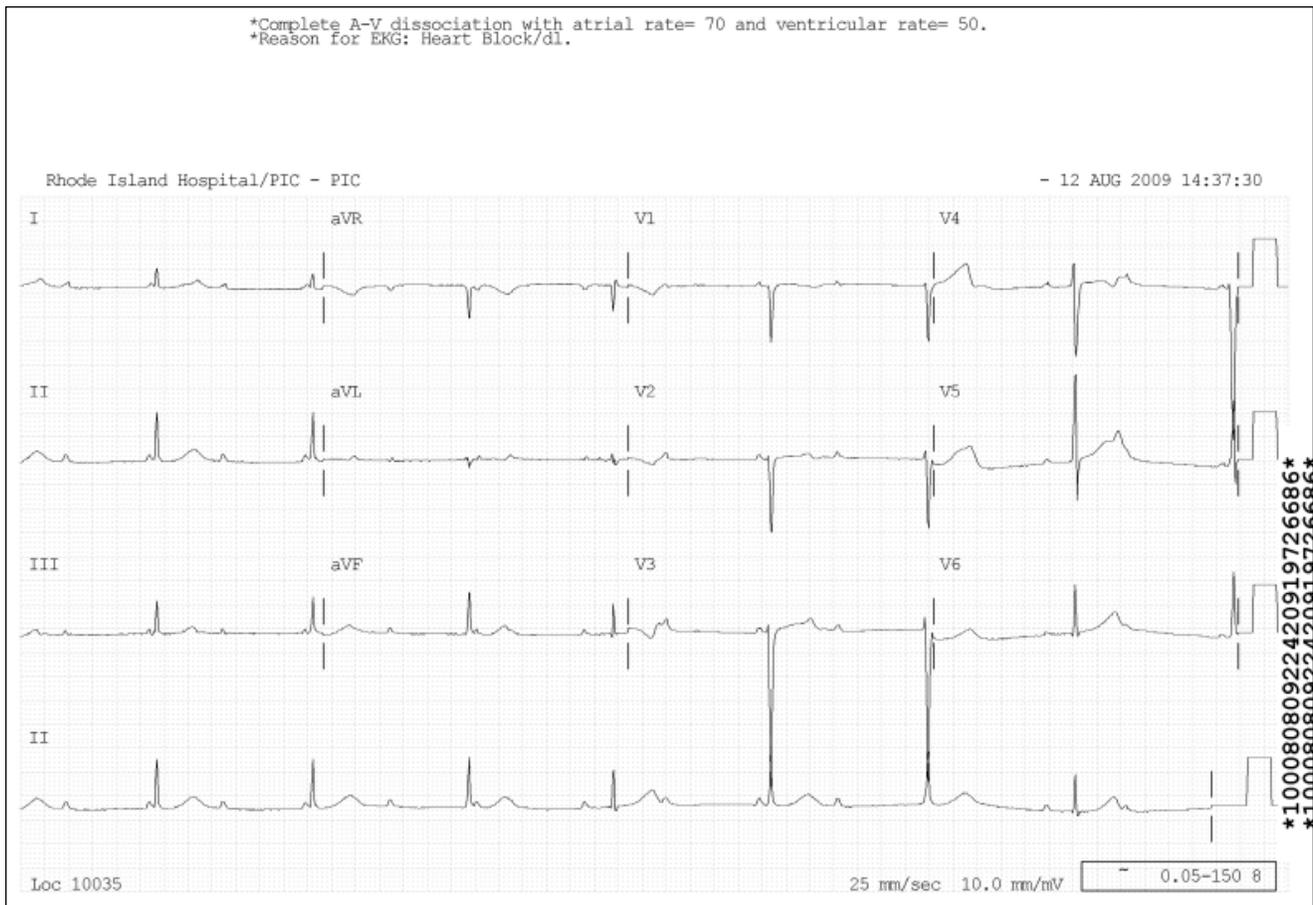


Figure 1. EKG upon arrival to the pediatric intensive care unit showing complete atrioventricular block.

EKG on day 2 of hospitalization showed complete heart block with periods of 2:1 AV block. EKGs were repeated daily for 3 days. A PICC line was placed for long-term antibiotic treatment. Lyme enzyme immunoassay was positive, as well as confirmatory IgM and IgG Western blot, which confirmed recent infection. On the fourth day of hospitalization the patient was discharged with instructions to avoid vigorous activities. He was to continue ceftriaxone for 21 days and to follow up with the cardiologist.

## DISCUSSION

Cardiac complications including conduction system disturbances such as varying degrees of AV block, myopericarditis, and congestive heart failure are possible manifestations of early disseminated Lyme disease.<sup>3</sup> In general, recovery occurs in greater than 90% of treated patients, although temporary cardiac pacing is sometimes necessary.<sup>4</sup> In a recent study of patients with advanced heart block, the median time to resumption of sinus rhythm was 3 days.<sup>5</sup> Late complications such as dilated cardiomyopathy may occur. Although echocardiography usually shows normal myocardial function in acute Lyme disease, it is a reasonable study in patients with depressed ventricular systolic function<sup>5</sup> and a useful tool to monitor for dilated cardiomyopathy secondary to Lyme disease.<sup>4</sup> A diagnosis of Lyme carditis should be considered when systemic features of Lyme are present, there is serological evidence of current or recent infection, and there is epidemio-

logic exposure. Rarely, complete heart block is the presenting complaint and only manifestation of illness.

A positive Lyme western blot IgM is generally obtained for establishing the diagnosis of an acute infection. In order of decreasing incidence, the following are the most common cardiac manifestations: AV block (77%), pericarditis (16%), intraventricular conduction disturbance or bundle branch block (13%), and heart failure (13%).<sup>3</sup> In the case of complete heart block, there is often a progression through intermediate degrees of heart block to first-degree heart block and ultimately normal AV conduction, as demonstrated in this case report. Heart block most commonly involves the AV node, but can occur at the sinoatrial node and intra-atrial conduction system as well.

Antibiotic therapy should be initiated to prevent progression to late illness. The Infectious Diseases Society of America as well as the American Academy of Pediatrics recommend treatment with intravenous ceftriaxone for 14 to 21 days in children with carditis. Amoxicillin, cefuroxime, and doxycycline are also acceptable treatments. Atropine sulfate may be considered for treatment of symptomatic bradycardia, but is usually not efficacious in Lyme carditis. Pacing is a possible modality in symptomatic patients and Costello notes a need for temporary pacing in 12% of patients studied. It is reasonable to refer children with severe myocardial dysfunction to pediatric cardiology centers with ECMO capabilities: this may be a life saving intervention in such patients.<sup>5</sup>



Figure 2. Rhythm strip demonstrating progression to second degree heart block.

Outpatient follow-up is appropriate in patients without high degree AV block or PR intervals greater than 300 ms. A restriction of vigorous activity is advised in those patients with a minor prolongation of the PR interval.<sup>7</sup>

It is unclear how repeated infection with Lyme at this age has contributed to the severity of the patient's cardiac disease. Studies should be conducted in endemic areas to elucidate what effect reinfection may have on the myocardium and the conduction system.

### CONCLUSION

Lyme carditis is a rare finding in children. To our knowledge this is the youngest documented case of asymptomatic complete heart block in the literature. Further investigation into the risk of carditis in patients with an extensive history of Lyme disease is necessary.

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# Recognition and Management of Extended Spectrum Beta Lactamase Producing Organisms (ESBL)

*Sophia Fircanis, MD, and Maria McKay, RN, MA, CIC*

**Urinary tract infections (UTI)** are one of the most commonly diagnosed infections, and typically among the most easily treated infections in the young and healthy. Emerging over the last twenty five years is the growing problem of **extended spectrum beta-lactamase (ESBL)**-producing organisms which cause UTI. ESBL organisms produce enzymes that hydrolyze the beta-lactam ring of beta lactam antibiotics like penicillins and cephalosporins, rendering them ineffective. Beta lactamase producers are typically gram negative organisms, namely *E. coli*, *K. pneumoniae* and *Klebsiella oxytoca*. However, ESBL production has also been observed in Proteus, Pseudomonas, Serratia, Enterobacter, Salmonella, Acinetobacter and Citrobacter species, among others. The gene for beta-lactamase production appears to be carried on plasmids which can be easily transferred from bacteria to bacteria. ESBL-producing bacteria inactivate the following antibiotics: beta lactams, extended spectrum cephalosporins, monobactams, and cephamycins. In addition to, or as a by product of their evasiveness to antibiotic therapy, ESBL organisms are more likely to produce invasive disease and yield higher mortality. The only proven therapeutic option for severe infections caused by ESBL-producing organisms is the carbapenem family of antibiotics: imipenem, meropenem, and ertapenem.

While ESBL infections may present with typical UTI symptoms, in the elderly population it is important to consider asymptomatic or atypical presentations. Dysuria, urinary frequency and fever may be not be evident, or may be confused with symptoms of other disease processes; i.e., benign prostatic hypertrophy, bladder dysfunction, etc. Common findings in the geriatric population associated with UTI include a change in energy level, or lethargy, mental status changes, confusion, new or increased combativeness, or, in patients with dementia, a rapid change in baseline cognitive or behavioral state. Since many of these symptoms are non-specific, diagnosis in older adults can be challenging. Several clinical criteria can assist in determining diagnosis:

- The McGeer criteria for nursing home residents are often used and cited. These criteria propose that 3 of the following must be met to diagnose a UTI: (1) a temperature of 38 C (100.4 F) or higher; (2) new or increased burning sensation on urination, frequency of urination, or urgency of urination; (3) new flank or suprapubic pain/tenderness; (4) change in character of urine; and (5) worsening of mental or functional status.

- Other guidelines for UTIs were proposed by Loeb et al. and can also be useful to determine necessity for empirical antibiotic therapy. For nursing home residents, the Loeb criteria suggest empirical coverage in the setting of: acute dysuria alone or fever (a temperature of greater than 37.9 C (100F), plus at least 1 of the following: new or worsening urgency or frequency of urination, suprapubic pain, gross hematuria, costovertebral angle tenderness, or urinary incontinence.

These criteria are used in conjunction with **urinalysis (UA)** results. Typically a patient, to be diagnosed with UTI, should have findings on UA that raise concern for UTI such as pyuria, bacteriuria or evidence of leucocyte esterase, blood or other abnormal cells. These findings in conjunction with the above diagnose UTI. In some patients there is pyuria, bacteriuria or both without the clinical findings above; these patients are considered asymptomatic and do not require treatment. These criteria, while useful in the geriatric population, are not recommended in patients with additional risk factors like indwelling devices like urinary catheters.

A note about asymptomatic bacteriuria – this is a common condition where urine gram stain and/or culture are positive, but there are no symptoms, typical or atypical, of infection. This clinical situation is found in up to 50% of women and 30% of men over the age of 65. It is not associated with any of the adverse outcomes typically seen in urinary tract infections, and does not necessitate treatment.

## RISK FACTORS

UTIs are more common in individuals with a history of UTI, incontinence, neurologic or cognitive impairment, poor nutrition, immunosuppression, or other comorbid disease states. Multidrug resistant organisms can be found more commonly in individuals who are frequently hospitalized, live in a nursing home or other institutionalized long term care facilities. UT's in the elderly patient are more likely to be due to more complicated bacterial origins than simple gram negative infection. Gram positive infections as well as mixed infections with multiple flora are seen more frequently, necessitating broader spectrum antibiotic coverage than simple gram negative coverage alone. In addition, multidrug resistant organisms are seen more frequently in this population, necessitating more complicated therapy.

These organisms, like most **multi drug resistant organisms (MDROs)**, are associated with certain risk factors; i.e., Institutionalization, previous use of any antibiotic, previous hospitalization, ICU stay, age, chronic underlying disease, G-tubes, abdominal surgery, urinary catheters, and gut colonization. Gender plays very little, if any, role in risk.

## TREATMENT

First-line therapies are drugs in the carbapenem family of antibiotics. Meropenem 500 mg intravenously three times a day is a standard antibiotic regimen for ESBL. Carbapenems are effective, but evidence is based mainly on observational studies. In addition, they have a number of treatment considerations. They must be administered parenterally and are costly. Meropenem can cost up to \$150/day, at \$50/dose. The carbapenems do have a wide spectrum of activity; however, this very asset can become problematic. The widespread activity can promote infections with other organisms such as yeast and other bacterium. In addition, there has been recent evidence of selection for carbapenem resistant organisms. Carbapenem resistance is a growing problem, and there are few agents with limited activity that can be used to treat these organisms. Fosfomycin, and tigecycline have shown some activity against ESBL organisms, but other options are limited. The emergence of carbapenem resistant gram negative rods is a major clinical concern. Always striving for the narrowest spectrum antibiotic possible for treatment of an infection is critical to stem the tide of MDROs.

Acute infections can be resolved with antibiotic treatment. However, colonization is an issue for patients who have a history of an ESBL infection. There is no agreed upon way to screen for continued GI colonization. Even if urine cultures are negative after treatment, there is evidence to suggest gastrointestinal colonization and skin colonization persists indefinitely. Numerous institutional outbreaks have been reported with ESBLs. Transmission occurs through direct and indirect contact. There is ample epidemiological evidence that MDROs are carried from one person to another via hands of healthcare workers. Hands are easily contaminated during the care giving process or from contact from the environmental surfaces in close proximity to the infected or colonized patient. Patients

with a history or known infection with and ESBL gram negative bacteria should be placed on contact precautions in acute care hospitals. Strict adherence to hand hygiene compliance and environmental cleaning is imperative. Attention to the patient's personal hygiene and containment of urine and feces is also imperative with these patients.

## SUMMARY

ESBL organisms provide a continuing challenge in the geriatric community. They are increasingly prevalent, and pose unique challenges in treatment. Carbapenems are the mainstay of therapy; however they are expensive medications that require prolonged intravenous administration. Carbapenem resistance is a growing concern among frequently hospitalized patients and nursing home residents, and options for treatment of MDROs are limited. Attempts at minimizing the spread of beta-lactamase producers through hygiene and contact precautions are imperative, as is ongoing research into more effective antimicrobial agents.

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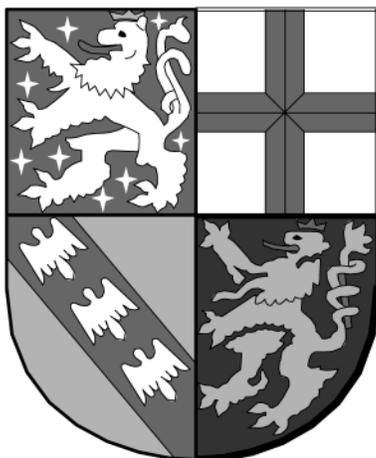
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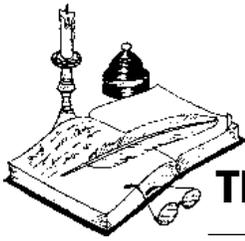
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# Physician's Lexicon

## Those Esoteric, Exoteric and Fantabulous Diagnoses

**Medical terminology is a living, constantly expanding, assemblage of terms with its population ever increasing as new diseases, innovative procedures and revised etiologies are discovered.** And thus, in our rush to learn new medical words, we have allowed many of the older terms to wither from extended disuse. A few of these languishing words are listed, and redefined, below.

Medicine is renown for its identification, and naming, of obscure fears. But many of these acknowledged phobias have lately been unacknowledged. **Blennophobia**, the fear of slime, has rarely been diagnosed although the medical profession has often used the root, *blenos* (Greek, meaning mucus) in a variety of words such as blennorrhea, blennostasis and blennophthalmia. **Gamophobia**, a fear of marriage, uses the Greek root, *gametes/gamete*, meaning husband or wife, and forms the basis for more popular words such as gametocyte and gametogenesis. **Demophobia**, on the other

hand, describes fear of crowds of persons, married or not, and is distinguishable from **agoraphobia**, the fear of open spaces whether or not crowded with people.

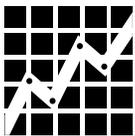
**Kakorraphiophobia**, the morbid fear of failure, derives its root from the Greek word, *kakos*, meaning bad as in cacesthesia signifying any abnormal sensation. The root should not be confused with the Latin, *caco*, meaning defecation. **Metrophobia**, the fear of poetry, defines a very rare emotional disorder found largely in elementary school children. The Greek, *metron*, means a measure, in this case, poetic meter; it is not to be confused with *metra*, meaning uterus, as in the word, metrorrhagia.

In contrast, there are those clinical words pertaining to an excessive adoration of something such as **ailurophilia**, an abnormal love of cats. The Greek, *ailouros*, means cats. **Lygophilia**, a love of darkness, descends from the Greek word, *lyge*, meaning twilight.

Words employing the root, *-phrenia*, generally define mental disorders such as schizophrenia. Someone who is frenetic (formerly spelled phrenetic) is a victim of fanatical frenzy. **Epistemophrenia** defines individuals with a pathological preoccupation with the acquisition and retention of knowledge. Epistemology is generally defined as that segment of philosophy that studies the origin, nature and limits of human knowledge. This is in contrast to **eschatophobia**, the fear of terminal events such as death.

And finally, a few obscure manias. **Drapetomania**, is the inordinate desire to run away from home; **Phaneromania**, is the compulsion to lick at or scratch one's skin; **Clinomania**, is the compulsion to stay in bed; **Habromania**, is the experiencing of extreme joy, euphoria. And **Onychophagia**, the biting of one's nails, might also be included in the category of the manias.

— STANLEY M. ARONSON, MD



RHODE ISLAND DEPARTMENT OF HEALTH  
DAVID GIFFORD, MD, MPH  
DIRECTOR OF HEALTH

## VITAL STATISTICS

EDITED BY COLLEEN FONTANA, STATE REGISTRAR

### Rhode Island Monthly Vital Statistics Report Provisional Occurrence Data from the Division of Vital Records

Underlying Cause of Death	Reporting Period			
	May 2009	12 Months Ending with May 2009		
	Number (a)	Number (a)	Rates (b)	YPLL (c)
Diseases of the Heart	212	2,450	233.2	3,032.5
Malignant Neoplasms	172	2,247	213.8	6,230.0
Cerebrovascular Diseases	36	410	39.0	752.0
Injuries (Accidents/Suicide/Homicide)	52	552	52.5	8,995.5
COPD	31	469	44.6	327.0

Vital Events	Reporting Period		
	November 2009	12 Months Ending with November 2009	
	Number	Number	Rates
Live Births	909	12,191	11.4*
Deaths	787	9,605	9.0*
Infant Deaths	(5)	(81)	6.6#
Neonatal Deaths	(5)	(64)	5.2#
Marriages	323	6,237	5.8*
Divorces	227	3,094	2.9*
Induced Terminations	289	4,195	344.1#
Spontaneous Fetal Deaths	32	699	57.3#
Under 20 weeks gestation	(28)	(618)	50.7#
20+ weeks gestation	(4)	(81)	6.6#

(a) Cause of death statistics were derived from the underlying cause of death reported by physicians on death certificates.

(b) Rates per 100,000 estimated population of 1,050,788

(c) Years of Potential Life Lost (YPLL)

**Note:** Totals represent vital events which occurred in Rhode Island for the reporting periods listed above. Monthly provisional totals should be analyzed with caution because the numbers may be small and subject to seasonal variation.

\* Rates per 1,000 estimated population

# Rates per 1,000 live births

### **NINETY YEARS AGO, MAY 1920**

Dennett L. Richardson, MD, in "Analysis of 100 Deaths from Diphtheria," noted that 17,114 patients died from diphtheria in 1917 in the US. "No matter how many cases of diphtheria a clinician may have seen, he cannot always pick out diphtheritic throats from physical appearance nor from the character of the symptoms." Dr. Richardson urged clinicians to take cultures of every sore throat. Both cultures and antitoxins had arisen at the same time, leading to an increase in reporting of diphtheria. He chronicled 100 consecutive deaths at Providence City Hospital from faucial or naso-faucial diphtheria (he excluded laryngeal diphtheria). Only one decedent was younger than one year; 43 were ages 1 to 4, 42 ages 5 to 9. Ninety percent of deaths happened in the first two weeks; very few patients had received antitoxin. "It is of much importance to be able to predict when called to treat a case whether the patient will recover or die." Death was usually due to circulatory failure.

An Editorial, "The Milk Campaign," warned of "...an attempt to evade the law by certain producers and to foist an unclean and dangerous product upon the innocent consumer." The Editorial also urged physicians to encourage their patients "to drink milk in spite of the prevailing price."

A second Editorial, "The Workings of the Maryland Plan," noted that the Washington County Medical Society had passed a resolution requesting each member to report to the Secretary on his financial relations with servicemen. At the start of World War I, most medical societies passed resolutions adopting the Maryland plan, so that physicians at home who treated the patients of physicians serving overseas would compensate those physicians.

### **FIFTY YEARS AGO, MAY 1960**

Alex M. Burgess, Sr, MD, the Chair of the Conference on Aging for RI, had gone to Israel for a month as part of an exchange team of physicians from Miriam Hospital. He contributed "Care of the Aged in Israel." Specifically, he detailed the care of 5000 elderly immigrants, who were classified into one of four groups: able-bodied, infirm, needing non-skilled assistance, needing trained nursing, chronically ill patients needing hospitalization. From the start the social worker determined the capacity for work: "When accepted for care a person is studied to determine his work ability. If it is found that he is able to work, even for a short time each day, arrangements are made for him to do so."

Edwin Dunlop, MD, in "Experience with a New Psychic Energizer," described a study, with 77 patients, "to determine whether mild to severe depressions could be managed with drugs alone, as well as to compare, or combine imipramine and electroshock therapy in patients who had previously been treated with the latter alone." The researchers found: "Imipramine should not be confounded with tranquilizers nor is its mode of action

that of monoamine oxidase inhibition. It relieves the depressive condition but does not act as a stimulant..." After the study, twenty-two patients who had previously been treated with electroshock therapy were treated solely with medication.

### **TWENTY-FIVE YEARS AGO, MAY 1985**

Paul J. M. Healey, MD, in "Medical Discipline and the Malpractice Crisis," noted that in 1976 the General Assembly created Rhode Island's Board of Medical Review as part of tort reform. Financial assessments from physicians and hospitals financed the Board. A March 21, 1986, *New England Journal of Medicine* article, however, ranked Rhode Island 45<sup>th</sup> in disciplinary actions against physicians (1982 data). That year, the Board applied sanctions against only 1 of the 1782 license-holders. Dr. Healey asked: "What do the physicians of RI have to show for the \$110,000 yearly assessment which they pay for the Board's operational costs?"

Elliot Lerner, ScB, and Tom J. Wachtel, MD, in "Thyrotoxic Periodic Paralysis, Case Discussion and Review," explained that the "...pathogenesis of the disorder is unclear, but is presumably secondary to hypokalemia.

Dianne N. Abuelo, MD, Judith Rosenstein, BA, MT (ASCP), and Michael Sheff, PhD, contributed "Tay-Sachs Disease: Knowledge and Attitudes of the Rabbinical Community." The RI Tay-Sachs Prevention Program had been operating since 1972: more than 2000 people had been tested, and 105 carriers identified. The Program sought to enlist rabbis in the outreach, since premarital counseling was an ideal opportunity to encourage screening.



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Your reputation matters. Period.

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Some insurers cap their defense costs or take them from your coverage limits. NORCAL Mutual does not. We are committed to protecting you regardless of the cost.

*There is no cap on the value of the reputation you've earned.*



Call RIMS Insurance Brokerage Corporation at 401.272.1050 to purchase your NORCAL Mutual coverage. Or, visit [www.norcalmutual.com](http://www.norcalmutual.com).

NORCAL Mutual is proud to be endorsed by the Rhode Island Medical Society as the preferred medical professional liability insurer for its members.