

# Virtual Mentor

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## From the editor

### Parents, children and their physicians: the complex journey of parenthood

In 1890 the city of Chicago competed with other American cities to be the staging ground for the 1893 World's Fair. Americans were worried that they had lost international prestige after the glamorous and exotic Parisian Exposition of 1889, which most visitors felt could not be surpassed. Chicagoans had additional motivation in securing the event for their city; they wanted to show the country and the world that they weren't citizens of a "greedy hog-slaughtering backwater"[1]. Congress ultimately approved Chicago as home to the fair, called The World's Columbian Exposition in celebration of metropolitan man and "four centuries of progress" since the discovery of the New World.

Organizers mounted a glittering affair. Lake Michigan provided the setting for the most accomplished architects, sculptors and landscapers in the country who participated in designing the monumental fairgrounds. When the fair's "splendid fantasy"—"a realization of Utopia" [2]—came to an end in 1895, a gray, sooty, chaotic, metropolis was left behind, one that was suffering a significant economic downturn. In the midst of the dreariness, one of the elegant, glittering buildings—for which the fair had been dubbed the "White City"—was given to the "Gray City," as post-1895 Chicago was described. A replica of the La Rabida monastery, the location from which Columbus had set sail to the New World, had been built in Jackson Harbor. During the fair, La Rabida housed relics of the historic voyage. After 1895, the Spanish Consulate made a gracious gift of the building to the city for use as a fresh air sanitarium for sick children.

Decades later, the hospital gained international recognition for research that led to the eradication of rheumatic fever and made a further commitment to treat chronic illnesses of childhood including arthritis, asthma, cerebral palsy, diabetes, Down syndrome, lupus, sickle cell disease and developmental disabilities. In the latter 20th century and into the present, La Rabida has been a leader in the state of Illinois for an extensive hospital-based program for neglected and abused children [3]. It continues to function as a hospital for sick children with the additional mission, declared by its Women's Board over one hundred years ago, to provide relief for the "tired and weary mothers" of the city.

Reaching across economic, racial and health barriers, La Rabida has embraced the gray city and through family-focused care has started, enriched and kept alive a

dialogue about the medical, social, political, legal, technological, moral and ethical issues facing the parents and families of sick children. It is one of only two remaining buildings from the original White City. La Rabida Children's Hospital, one of the teaching hospitals at the University of Chicago, was the site of my third-year clerkship in pediatrics and the inspiration for this issue of *Virtual Mentor*.

In this issue, we explore the extraordinary challenges pediatric physicians and the parents of their patients face together in this setting and in other clinical environments. In her case commentary, Dianne McBrien explores the complexities of raising children with mental disabilities and the ethical challenge doctors face in helping these children achieve their potential for independence. Next, we enter the complex and heart-breaking sanctuary of a dying child to explore how we might comfort his mother. Peter Smith's commentary on this case invokes an ancient ethical tradition, virtue ethics, to remind us that compassion for this child's parent is "the ultimate hope for a virtue ethicist." Sharon Hirsch and Rebecca Sheffield discuss the case of a nine-year-old girl with conduct disorder and the complex set of ethical issues and social biases confronting families and physicians who care for children with psychiatric illness. Through a case of adolescent obesity, Joseph Zanga and John Moskop draw our attention to the cultural and developmental complexities that often determine whether physicians are able to achieve lasting benefits. The clinical pearl written by Suma Jacob supports Dr. Hirsch's piece by describing current diagnostic criteria and treatment for conduct disorder.

Emily Anderson reviews a chapter of Lainie Friedman Ross's book, *Children in Medical Research: Access Versus Protection*, about twin aspects of informed consent in pediatric research—parental permission and child assent. She supplements her journal discussion with data from a number of articles that show a disturbing lack of understanding among parents who consent to research protocols for their children. Lee Black's piece on health law examines how the law sorts through parents' "willingness to make medically appropriate decisions" on behalf of their children. He looks at how the courts decide cases where the parental decisions for or against medical treatment are grounded in religious and nonreligious belief. In the policy forum, Nancy Berlinger examines the health and social consequences of parents' decisions not to have their children immunized against common childhood diseases.

In his thoughtful essay on medicine and society, "Talking with families about severely disabled children," Arthur Kohrman discusses the struggles faced by parents of disabled children. He offers physicians a glimpse of the psychological despair and unnerving demands placed on parents of children who will never realize the promise of childhood and a strategy for building long-term empathic relationships with these parents. David Collier and Joseph Zanga, in their medical education essay, revisit childhood obesity, a topic of growing national concern. It is now estimated that one out of every three children is overweight, increasing their risks for cardiovascular disease, diabetes mellitus, cancer and chronic disease. Drs. Collier and Zanga discuss ways residency programs can impart skills needed to encourage family health. In the

medical humanities section, I review the unique relevance of Francois Truffaut's film "The 400 Blows" for physicians who work with children.

Unfortunately, we do not have the space to examine other significant ethical issues facing parents: the alarming incidence of failure to thrive among toddlers in this country; the difficulties in treating children who live in chronic pain; the escalating problem of urban diseases like asthma and the particular challenges that these diseases pose. We have not examined severe cases of child abuse. Children hurled against walls or scalded across their buttocks, thighs and scrotum for failing to master potty-training. Neither have we the space to celebrate parents who have sacrificed careers, who live for long stretches of their lives in hospital rooms advocating tirelessly for their children. Parents who willingly carry their children, including their adopted children, to the furthest reaches of the globe seeking medical treatment because for them it is the right thing—the ethical thing—to do and because for some of these remarkable parents the journey they take with their sick children represents a mutual embrace.

Disparate styles of parenting are often on display in doctors' offices and in hospital settings. Parental behaviors become the source of derision, disbelief and sometimes awe. It's clear to most doctors and residents that adults come to their roles as parents with various levels of preparation, competence, desire and vision. The task of educating parents into parenthood is complicated. Our strategies for helping families make this important transition need to be grounded in basic, clinical or translational research. Current strategies are not well-grounded, but it's clearly an area of growing concern. For example, the Society of Behavioral Neuroendocrinology has recently organized the Parental Brain Conference to "bring together basic and clinical researchers using state-of-the-art scientific approaches to examine the role of the central nervous system in maternal and paternal care" [4]. The meeting will focus on neural adaptations of the maternal and paternal brain towards parenthood with emphasis on postpartum mood disorders, inadequate parental bonding, parental aggression and anxiety.

I am pleased that, through the serendipitous interweaving worlds of research and publishing (themselves forces of nature), this issue of *Virtual Mentor* coincides with the recent report published in *Nature* of a well-preserved 3.3-million-year-old juvenile skeleton, a three-year-old female *Australopithecus afarensis* discovered in Dikika, Ethiopia [5]. Scientists believe that this archaic hominid found buried in the sediments of a river basin, this "precious bundle" of skeletal remains, will provide crucial insight into the evolutionary history of man [6]. We hope the Dikika toddler, now carefully excavated, will shed new light on the long complicated history of who we have been. As the cases and themes our authors wrestle with demonstrate, scientists and the public alike remain anxious to discover, through ongoing investigations, what sort of parent our ancient ancestor will ultimately become.

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### References

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