

CONGENITAL CARDIOLOGY TODAY

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BILLING SCHADENFREUDE

By J. Deane Waldman, MD, MBA

Introduction

We must start looking at our healthcare system as our patient, rather than focusing exclusively on individuals as our sole responsibility. Once you apply your diagnostic acumen to this larger patient, you will see that we are treating a growing cancer with soporifics and painkillers. We need to look no further than our bills to see the patient's decline, manifest by increasing complexity producing confusion and progressive dementia all in the name of accuracy, clarity and simplification, as well as attempts to regulate or even legislate good behavior.

When doctors bill for services, what they experience is a game with inconsistent rules and contradictions, a game they cannot win. For instance, the business industry standard of "thirty-day triple net" is unheard-of in the business of healthcare. Delayed payments and eroding reimbursement rates are a constant

reality, but these are symptoms, not causes, of dysfunction. The primary etiologies for billing schadenfreude are agency confusion and micro-economic disconnection.[1]

Agency Confusion

Before submitting your bill, ask yourself this question: whose agent am I? Your choices are four P's, stakeholders called: Patient (also known as client, customer or consumer, depending on your viewpoint); Provider (yourself or nurse or allied health person); Payer (private, agency or governmental); and Practice (organization – hospital, Faculty, medical system). If you answer that you *work for* more than one "P", you must indicate the rank order. Each stakeholder

has a different preferred outcome. The Patient wants to be well and damn the cost. The Provider wants to offer good care and to make money (hopefully in that order). The Payer wants to generate profit by not spending money at all or by spending the least amount possible or by deferring payment as long as they can get away with it. Klienke expressed it all too well: "The principal goal of the consumer finance industry is to in-

"It is disheartening, but true, that our billing woes generate profits for payers. It would be insufferable, but is entirely possible that our pain produces pleasure in others (schadenfreude from German). Given that we understand the etiology of the [billing] disease, we should be able to offer treatment."

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crease the number of transactions. By contrast, the principal goal of the health insurance industry is to slow down transactions or lose them altogether.”[2] The Practice or organization wants to achieve its goals, which are multiple, often contradictory, and prominently displayed on the hospital entrance, but invariably leaving unstated its highest organizational priority: to survive, by having more revenue than expenses.

Micro-Economic Disconnection

Our healthcare system is plagued with divergence of stakeholder goals and micro-economic disconnection, which describes the mal-alignment (you knew a pediatric cardiologist would somehow get that word in) of the desired outcomes – among the stakeholders and across time.[3]

If you go to McDonald’s (*not* a heart healthy choice), you order the food (cost driver), you eat the food (consumer), you pay for the food (payer) and you judge whether it was worth the price. This is displayed as a simple, single feedback loop (Figure 1) within its own silo or system. Healthcare has a different organizational structure.

The Patient starts the process (Figure 2) because of his/her problem and is the consumer, but not the cost driver. You – the Provider – serve that function. The Payer is the gatekeeper of money, but not the arbiter of quality or customer satisfaction. Feedback loops are all contained within their own silos with virtually no effective systematic feedback between Patient, Provider, Practice or Payer – positive or negative.[4]

What healthcare represents is micro-economic disconnection at its worst. The very mechanisms that make capitalism and free markets work well are subverted in our current healthcare system.

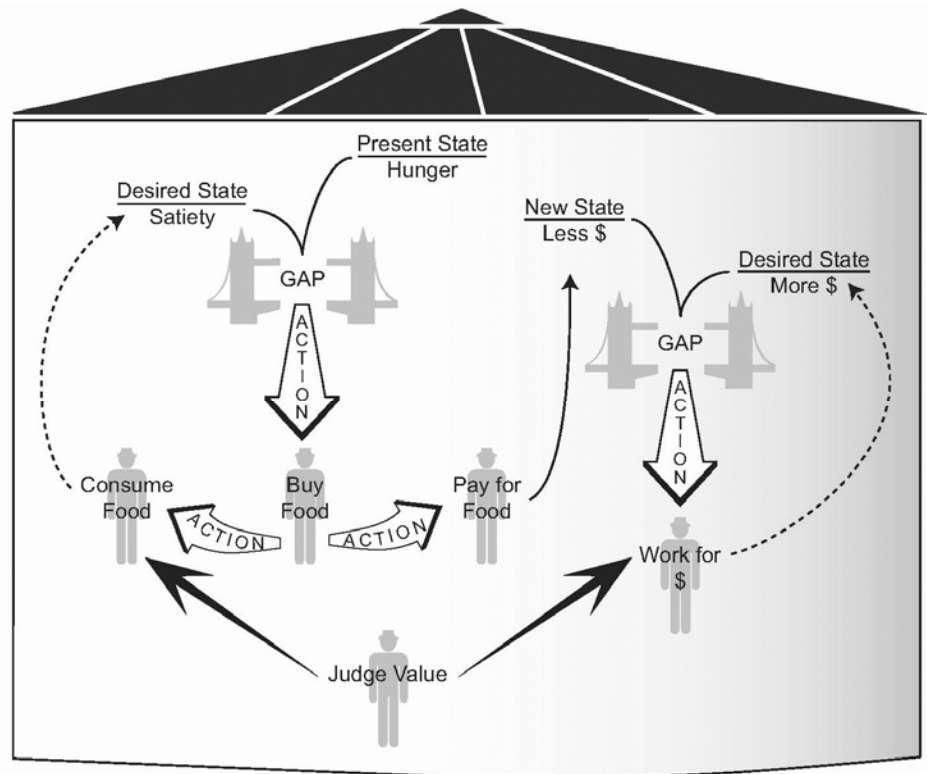


Figure 1. An Effective Feedback System – in a Single Silo

A standard schema of systems’ analysis is displayed for eating at McDonald’s. The individual has hunger and wants satiety, creating a “gap”. The gap induces the actions of paying for and consuming food, by the same individual who had the hunger. Paying for the food created a new gap (financial), which the individual rectified by working. The same, now satisfied (hunger-free) individual also judged whether the food (and work) were worth the McDonald’s price.

We labor under a disjointed combination of free market forces, mandates and price controls. Though health care providers work hard and mean well, “fixes invariably fail,”[5] and unintended consequences prevail. The message is clear: we need to treat root causes, rather than palliate symptoms. Russell Ackoff[6] described the four “solves” as follows: To *absolve* means to forgive; to *solve* means to make better; to *resolve* means to get the best result; and to *dissolve* – what we need to do in healthcare – requires changing the system so

that the original problem cannot recur. To dissolve our problems, we need systems thinking.[3,7]

The Billing Morass

Billing provides an excellent example of agency confusion, and dramatizes the need for systems thinking. When the doctor generates a bill, for whom is the doctor an agent, and where/what/to whom is the feedback? If the Provider is highest priority, then billing is focused on generation of personal revenue or its surrogate RVUs. Secondarily, you wish



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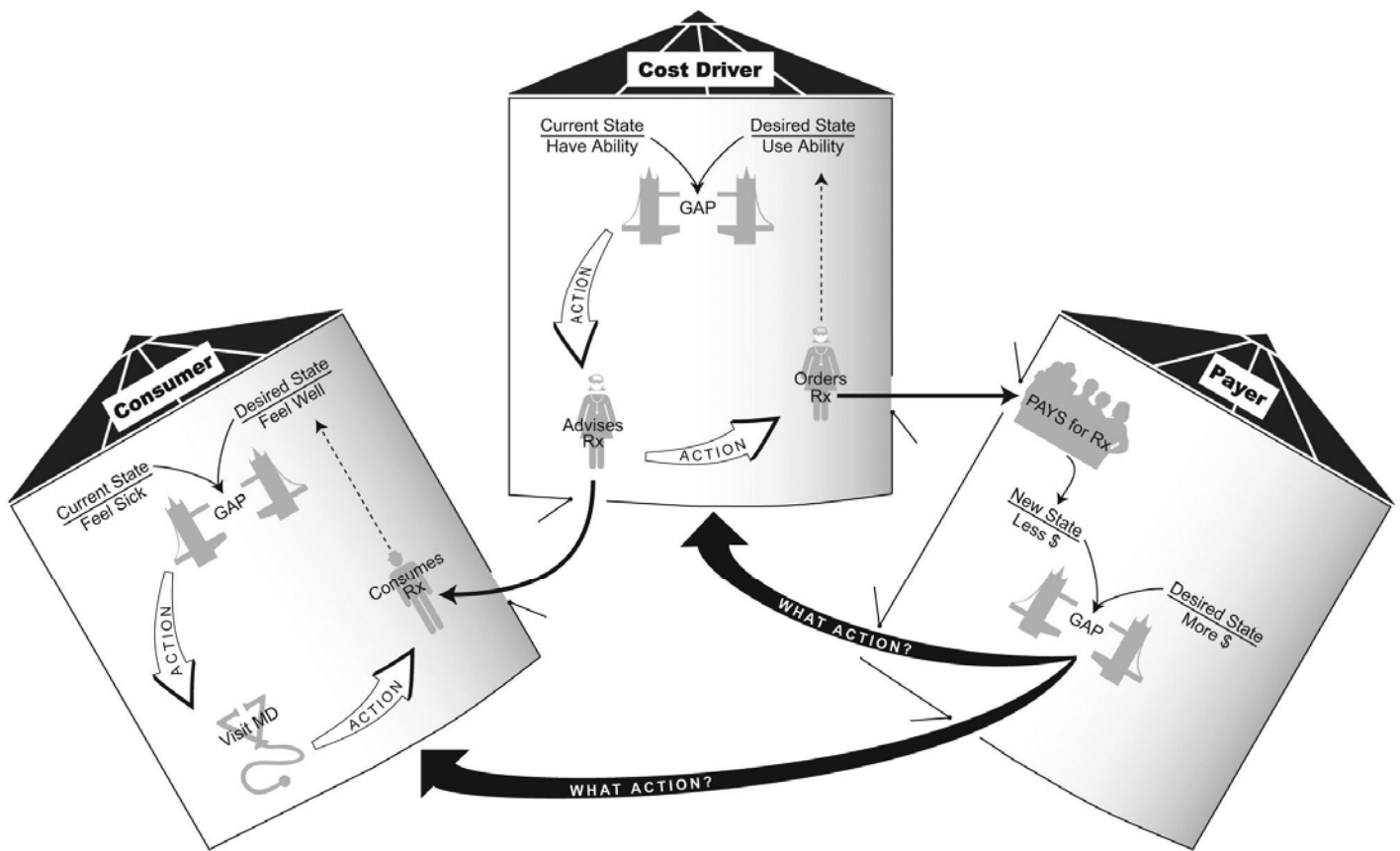


Figure 2. Healthcare – Silos and Micro-Economic Disconnection.

There are three separated systems or silos: Consumer (patient), Cost Driver (provider) and Payer. There is very limited interaction between silos, but the major feedback is contained within the silo and does not accomplish system-wide purposes:

- The Consumer experiences a gap between desired state (feeling well) and current state (feeling sick). The gap induces an action – going to the doctor (provider) – who recommends a treatment (viz., a medication) that the patient consumes and thereby feels better, achieving a resolution of the initial gap.
- The Cost Driver's gap – between having ability and using ability to heal – causes her to care for the patient. Consulting with the patient is followed by a recommendation for treatment such as a medication that creates an expense – a financial outlay that neither she nor the consumer pays.
- The Payer covers the cost of treatment and this creates a gap between the desire to have money and the obligation to spend money. To resolve this gap, the payer takes some action, affecting either the Consumer silo, the Cost Driver silo, or both.

Consider what action(s) are available to the Payers to resolve their Gap. Note the absence of effective feedback loops between Payer, Cost Driver, and Consumer. Contrast this system of three silos to the McDonald's loop in Figure 1.

to comply with regulations and avoid a lawsuit. If the Patient is top priority, and you recognize the implicit fiduciary responsibility (position of trust and de-

pendency), then you seek accuracy and to maximize patient benefit; this may include not labeling the patient with a diagnosis that unnecessarily and nega-

tively impacts his life. If the doctor has a financial relationship with the Practice, as virtually all do indirectly if not directly, then that may dominate the choice of

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billing codes. Additionally, healthcare organizations may change the billing codes, often without doctors' knowledge. The largest Payer is of course the government, and we – doctors, nurses, social workers, all taxpayers – are the ultimate payers for the cost of our healthcare system.

The current billing system has huge flaws. It is inefficient, very costly and a major generator of work-related dissatisfaction as well as turnover. Discordance of goals creates adversarial relations between Patient and Provider, Provider and Practice, and even Payer with Payer. The system actually increases the probability of adverse impacts and errors. Finally, the codes in the form of discharge diagnoses are reported to the Federal government, which in turn uses that information as epidemiologic and demographic *truth*. But if the codes are created for other than medical accuracy, what does that imply in re: governmental epidemiologic recommendations?

Health Information Systems (HIS)

There is widespread agreement that billing and medical information systems should be integrated. There is also a consensus that what currently exists does not satisfy the needs of patients, providers, payers or practices. So, why don't we have a HIS that works? The etiologies are market failure[2] and government paralysis. Specific reasons are delineated in Table 1.

The combination of multiple agendas without prioritization, technical concerns, corporate greed, and paranoia at multiple levels has hamstrung attempts to develop a functional national HIS. To this unholy mix must be added paralysis by expecting perfection. Trying to meet everyone's needs – some incompatible such as national security and unlimited

Table 1: Why We Do Not Have a National Health Information System	
• Specific Issues	
	Cost to create and implement
	Preservation of confidentiality
	Potential governmental control (Fear of "Big Brother")
	Technical concerns, including interoperability
• Systemic Dysfunction	
	Multiple, often contradictory agendas
	Inefficiency and sloth are profitable
	Unnecessary medical activities are profitable
	Lack of common language (debatable validity of assertion; see LOINC[8])
	Absence of evidence for managerial & regulatory decisions
	Paralysis by demanding (and expecting) perfection
• Excuses	
	Proprietary profit
	Increased oversight will cause increased lawsuits
	Defensive medicine

personal freedom or free exchange of information and guaranteed confidentiality – we have no system rather than a good, but imperfect one.

“What is my simple, cheap, quick and painless answer, my silver bullet? Sorry, all out today. Anyone who offers you such a magic potion also sells swampland and bridges to nowhere. Previous attempts to deal with, to solve or resolve, these problems have repeatedly produced adverse unintended consequences.”

The Answer – Blow it up

It is disheartening, but true, that our billing woes generate profits for payers. It would be insufferable, but is entirely possible, that our pain produces pleasure in others (*schadenfreude* from German). Given that we understand the etiology of the [billing] disease, we should be able to offer treatment.

What is my simple, cheap, quick and painless answer, my silver bullet? Sorry, all out today. Anyone who offers you such a magic potion also sells swampland and bridges to nowhere. Previous attempts to *deal with*, to solve or resolve, these problems have repeatedly produced adverse unintended consequences. HIPAA actually had some good intentions in its conceptualization! We need to create a new system, not



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tweak the one we have. It calls to mind the phrase, *rearranging deckchairs on the Titanic*. As proof of my assertion that only by blowing up what we have can we acquire what we need, consider attempts made by the Federal government to "harmonize" the medical information system to create uniform electronic billing (Personal communications, Jeff Blair, Vice President of the Medical Records Institute and Co-Chair of the Federal Subcommittee on Standards and Security of the National Committee on Vital and Health Statistics). This was started in 1996 and was seen as "low-hanging fruit," something they could pick easily, certainly within two years. Almost ten years later, do you see such a system in place?

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Correction in December 2005 Issue

In our "Medical News Products and Information" department (p.17), we reported that the *Directory of Pediatric Cardiologists* published by the Section on Cardiology & Cardiac Surgery (SOCCS) of the American Academy of Pediatrics is currently available on request. We reported this information prematurely. In the meantime, if you would like to have your name put on the list, please send and email with your name and address to:
DIRECTORY@CongenitalCardiology.com

The Division of Pediatric Cardiology at the University of Utah School of Medicine is Recruiting a Pediatric Cardiologist with a Major Interest in Adult Congenital Heart Disease.

The candidate should have a strong clinical background in all areas of pediatric cardiology with expertise in adults with congenital heart disease. The candidate will be joining a 14-member division of Pediatric Cardiology with two pediatric cardiologists currently involved with the Adult Congenital Heart Disease Program. This candidate will also work with members of the Division of Cardiology in the Department of Internal Medicine at the University of Utah to continue to expand the program in Adult Congenital Heart Disease. There will be protected time for clinical research with mentoring available within the Division for clinical research studies. The Division has a very active clinical program, currently seeing a large volume of adults with congenital heart disease. The Division also has a very active clinical research program and is one of the participating centers in the Pediatric Heart Disease Clinical Research Network funded by the NIH.

The successful candidate will receive a faculty appointment at the University of Utah. The Pediatric Cardiology Division is based at Primary Children's Medical Center, a tertiary referral center for a three-state area located on the hills overlooking Salt Lake City. The area offers an excellent quality of life with immense cultural and recreational opportunities close and available. The University of Utah is an Equal Opportunity Employer and welcomes applications from minorities and women and provides reasonable accommodations to the known disabilities of applicants and employees.

*Interested individuals should contact
Robert E. Shaddy, Professor of Pediatrics,
Division Chief of Pediatric Cardiology,
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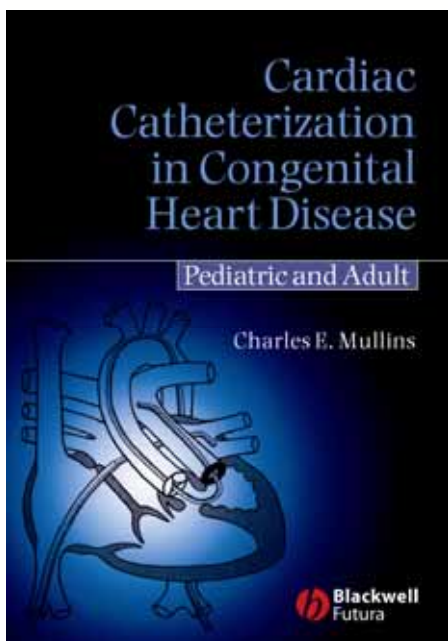
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BOOK REVIEW: CARDIAC CATHETERIZATION IN CONGENITAL HEART DISEASE- PEDIATRIC AND ADULT BY CHARLES E. MULLINS

By John W. Moore, MD

Cardiac Catheterization in Congenital Heart Disease - Pediatric and Adult is an exceptional book!



It is much more than I hoped for or expected. It is without doubt the most authoritative, the most comprehensive and the most detailed textbook about cardiac catheterization in congenital heart disease ever published.

There are 944 pages of text and 313 figures, divided among 35 chapters. Each chapter is well-referenced. Unlike most other familiar texts of this magnitude, Dr. Mullins wrote every chapter and every word. This is all his work. Most of the figures are instruc-

tive "free hand" line drawings contributed by one of Dr. Mullin's patients.

The chapters cover the entire range of topics which are of interest to cardiologists and other professionals involved with the catheterization of infants, children, and older patients having congenital heart disease. The initial topics are catheterization laboratory organization, and personnel and catheterization basics such as equipment, medications, patient preparation, tools for vascular access, wires, and catheters. Subsequently, diagnostic catheterization is fully discussed in chapters on right and left (transeptal and retrograde) heart catheterization, hemodynamics, and angiographic techniques. Finally, the bulk of the text and the majority of the chapters deal with interventional procedures and technologies, and follow in the order of their historical development. These chapters cover septostomy, valvuloplasty, angioplasty, stenting, occlusion procedures and devices, and cutting-edge technologies.

Clearly, there are too many chapters to mention all of their topics. Each chapter is a comprehensive, detailed treatment of its subject matter. For example, in Chapter 24, entitled "Intravascular stents in venous stenosis," Dr. Mullins examines this topic from every perspective. He provides a full discussion of appropriate equipment and stents, which complements a very detailed step-by-step description of how to do the procedures in a safe and reliable manner. His goal is to

"It is obvious that with this book, Dr. Mullins gives each of us a huge gift. In the Preface he tells us that 'the information contained in this text...represents the accumulation of knowledge, techniques, and procedures learned, utilized and/or developed by the author during the continued learning, practice and teaching, of cardiac catheterization procedures duringfour decades in the field.'"

emphasize both the fundamentals and the details. There are also sections covering totally obstructed venous channels, peripheral vein obstruction, and post-implant care. Stent implants in Fontan circuits are considered separately, as are pulmonary vein stents and pulmonary venous baffle stenting. The chapter ends with a discussion of complications unique to venous stents. Any cardiologist seeking education or information about venous stenting, need only study this one source.

It is obvious, that with this book Dr. Mullins gives each of us a huge gift. In the Preface he tells us that "the information contained in this text... represents the accumulation of knowledge, techniques, and procedures



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learned, utilized and/or developed by the author during the continued learning, practice and teaching, of cardiac catheterization procedures during ...four decades in the field." He notes further that catheterization of the patient with congenital heart disease requires "a thorough background knowledge of the normal and abnormal cardiac anatomy, a skill at catheter manipulation and an additional 'feel' for that anatomy." He hopes that this text will help cardiologists "in attaining the acquired skills, while the experience in using these techniques will provide the "feel!"

I was especially fortunate to have my fellowship training under Dr. Mullins. I am one of many who know him as a gifted teacher and mentor. *Cardiac Catheterization in Congenital Heart Disease - Pediatric and Adult* codifies Dr. Mullins' legacy in a definitive way. It will enable numerous present day and future cardiologists and their patients to benefit from his gifted teaching.

The book is dedicated to his wonderful wife Arlene; his mentor at Walter Reed Army Medical Center, Dr. Weldon Walker; and his friend, associate and chief for most of his tenure at Texas Children's Hospital, Dr. Dan McNamara. It was published in December 2005 by Blackwell Publishing, Ltd., Oxford, UK. The book is available for purchase from the Blackwell Publishing online bookstore at www.blackwellcardiology.com for US\$225.

~CCT~



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Assistant Professor/Associate Professor

The University of Louisville School of Medicine, Division of Pediatric Cardiology is recruiting two full-time board certified/eligible pediatric cardiologists at either the assistant or associate professor level to join a group of nine pediatric cardiologists.

Applicants should have a demonstrated interest in echocardiography (fetal, transthoracic and transesophageal) and hemodynamic catheterization (not mandatory). Responsibilities will include medical student/resident teaching, patient care and expansion of the clinical activities of the division. Interest in clinical research is encouraged.

Kosair Children's Hospital, the teaching hospital of the Department of Pediatrics, is located adjacent to the Medical School and its research buildings. The hospital draws from a population of approximately 2.5 million people, which results in a busy clinical program. Two full-time pediatric congenital heart surgeons at the hospital perform over 300 surgical procedures annually. The hospital offers state-of-the-art interventional and electrophysiologic services and the Department of Pediatrics, which numbers around 120 members, has a full range of subspecialists to support the cardiovascular program.

Salary will be commensurate with training and experience.

The University of Louisville is an Affirmative Action/Equal Opportunity Employer.

Applicants should send a letter and CV to Michael R. Recto, M.D., Director of Pediatric Cardiology, Department of Pediatrics, University of Louisville, 571 S. Floyd Street, Suite 334, Louisville KY 40202-3830. Telephone (502) 852-3876, Fax (502) 852-3877. email address: mitch.recto@louisville.edu



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PREVIEW OF CARDIOLOGY 2006: 9TH ANNUAL POST GRADUATE COURSE IN PEDIATRIC CARDIOVASCULAR DISEASE

By Gil Wernovsky, MD

Between February 8th and 12th, 2006, The Cardiac Center at The Children's Hospital of Philadelphia will host Cardiology 2006: 9th Annual Post Graduate Course in Pediatric Cardiovascular Disease—State of the Art Management of the Neonate and Infant with Cardiac Disease. After eight successful meetings in Orlando, this year's course will be held in Scottsdale, Arizona, at the Hyatt Regency Gainey Ranch and Spa. This course does not attempt to recreate the very successful subspecialty meetings for practitioners who care for children with heart disease; rather, a multidisciplinary approach combining neonatology, pediatric cardiology, cardiac surgery, nursing, anesthesia, critical care and perfusion will be taken. Over 90 faculty members from around the globe representing multiple disciplines and academic centers will present over 200 plenary and subspecialty lectures, and will feature three broad themes:

- common congenital heart disease: current management and controversies
- clinical trials and new research in pediatric cardiovascular disease, and
- ethical issues in the delivery of care to infants with cardiovascular disease.

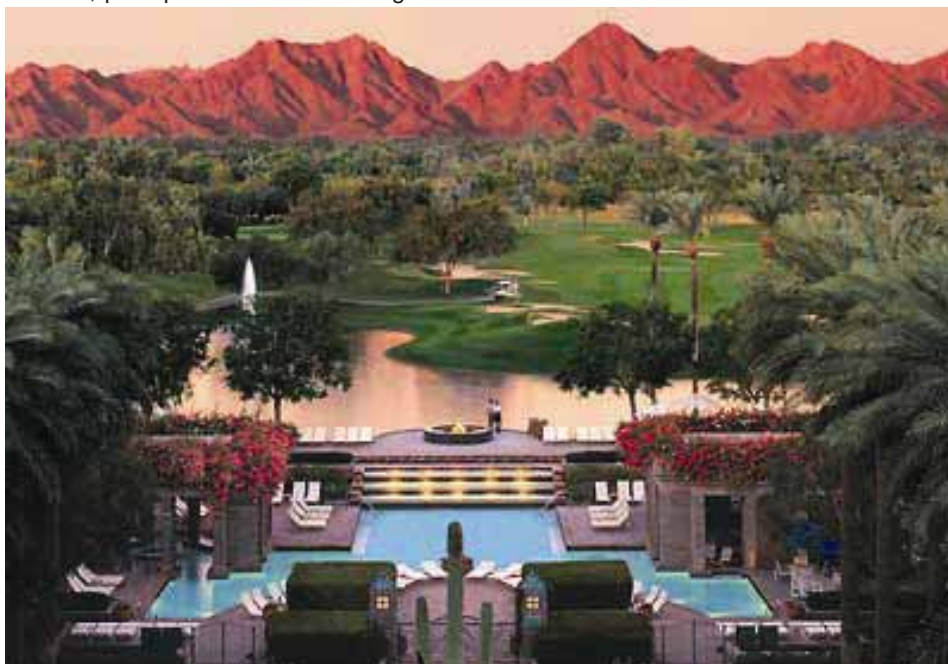
Daily plenary sessions are designed to be of interest to all medical, nursing and allied health professionals, with supplementary specialty-specific breakout sessions as well. Individual 'tracks' have been designed for neonatology and intensive care,

echocardiography, intraoperative care and perfusion, cardiac nursing, and administration.

The five comprehensive sessions on congenital heart disease will start with a review of anatomic specimens by Professors Robert Anderson and Paul Weinberg (including the controversies of nomenclature), preoperative imaging, surgical procedures, postoperative care and long term

Spray (Philadelphia), Mike Teodori (Phoenix), and John Mayer (Boston).

Three separate plenary sessions will be devoted to New Research and Clinical Trials. Dr. Skip Nelson will review regulatory issues in developing new drugs for children, Dr. Dave Wessel will review considerations in industry sponsored trials, and Dr. Gail Pearson will review the cur-



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results. Lesions that will be reviewed include transposition of the great arteries, ventricular septal defect, tetralogy of Fallot, aortic valve disease and hypoplastic left heart syndrome. Current surgical approaches will be described by Drs. Vaughn Starnes (Los Angeles), Thomas

rent status of the Pediatric Heart Network. New data on ICU pharmaceuticals (levosimendan, nesiritide, milrinone, esmolol), neurological outcomes after cardiac surgery, ABO incompatible heart transplantation, blood product utilization, and single ventricle surgery will be pre-



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sented. Dr. Redmond Burke will provide an overview of information systems, research and clinical care, and Dr. Rick Ittenbach will review important statistical considerations for all practitioners.

On Friday, February 10th, the afternoon session will be devoted to controversial topics and ethical dilemmas in our practice. Two pro-con debates will take place: "Should Non-surgical Care be Offered to Parents of Neonates with HLHS", and "Should Surgical Innovation be Monitored by Institutional Review Boards" (where Dr. Martin Elliot, a consultant surgeon from Great Ormond Street, will argue that new surgical procedures should be externally reviewed). End of life care, surgery in patients with lethal chromosomal defects and issues of informed consent will be reviewed. Finally, global perspectives on CHD care will be delivered by Dr. Daniel Penny (Australia) and Dr. Hiromi Kurosawa (Japan).

A special pre-conference seminar will be held (limited attendance) reviewing anatomic specimens and 3D echocardiography with Drs. Bob Anderson, Paul Weinberg and Girish Shirali. Dr. Shirali will also host a fabulous, two hour, hands-on session on 3D echo imaging on Friday, February 10th.

Over 40 abstracts will be presented in the young investigator award competition; the award will be given on Saturday, February 11th, in addition to the featured Rashkind lecture by Dr. Andrew Redington, the featured Lillehei lecture by Dr. Martin Elliot, and the featured Nursing Lecture by Ms. Kathy Mussatto.

Hope to see you in Arizona! Details and registration may be found at www.chop.edu/cardiology2006

~CCT~

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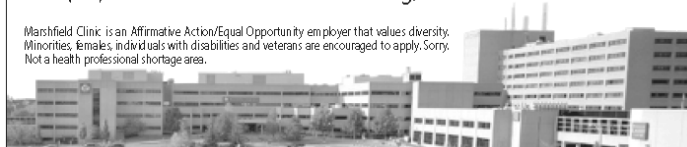
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Marshfield Clinic is a 700+ physician-directed multi-specialty group with 41 locations in central, northern and western Wisconsin practicing over 80 medical specialties. **Currently, we're seeking a third BC/BE Pediatric Cardiologist to join its tertiary facility in Marshfield, Wisconsin.** The right candidate will join a large pediatric department of general and subspecialty trained pediatricians. Opportunities exist for teaching and research with our pediatric residency and the Marshfield Clinic Research Foundation. A 504-bed acute care facility with a Level I PICU and Level III NICU adjoins the clinic on the medical campus.

Marshfield Clinic offers its physicians an excellent salary and benefits, along with the opportunity for personal and professional growth. Interested candidates may contact either of our pediatric cardiologists, Dr. Kathy Finta or Dr. Julie Dietz at (800) 782-8581 to learn more, or may submit their CV and questions to: Mary Treichel, Physician Recruiter, Marshfield Clinic, 1000 N. Oak Avenue, Marshfield, WI 54449, or call (800) 782-8581 extension 19774, or fax to (715) 221-9779; E-mail: treichel.mary@marshfieldclinic.org Check out our web site to learn more about Marshfield Clinic at: www.marshfieldclinic.org/recruit



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...PEOPLE ON THE MOVE

New Pediatric Specialist Joins Nemours Children's Clinic in Pensacola, FL

Pensacola, FL - Theresa Roca, MD, joins Nemours Children's Clinic in pediatric cardiology. She received her medical degree and residency training from the Tulane University School of Medicine in New Orleans, Louisiana. Dr. Roca's fellowship in pediatric cardiology was acquired from Tulane University School of Medicine and Alton Ochsner Medical Foundation Hospital where she remained until recently as an Assistant Professor. She is board certified in pediatrics as well pediatric cardiology. Dr. Roca joins William Blanchard, MD, Joseph P. Davenport, MD and Mary Mehta, MD, in a team approach to treating children with heart disorders.



For more information: www.nemours.org

The Children's National Heart Institute in Washington, DC is Expanding

Dr. David M. McMullan has joined the staff of the division of Cardiovascular Surgery. Dr. McMullan is a graduate of Tulane University and the University of Texas Southwestern Medical School. He completed his general surgery residency at the University of Texas and cardiothoracic surgery residency at the University of Washington. He received advanced training in pediatric cardiovascular surgery at the Royal Children's Hospital in Melbourne, Australia. Dr. McMullan has a strong interest in international medicine, working with Vietnamese clinicians to improve healthcare for children in Vietnam.

Dr. Achintya N. Moulick also joined the division of Cardiovascular Surgery at Children's in January 2005 after establishing the Fortis Healthcare Group, one of the largest hospital groups in Asia. At Children's, Dr. Moulick directs the Adult Congenital Heart Disease Surgery Program. Dr. Moulick did his initial training in surgery and cardiac surgery in Bombay, and subsequently completed his training

in cardiac and thoracic surgery at the University of Massachusetts, Worcester, Massachusetts General Hospital, Boston and Emory University Hospitals, Atlanta, respectively. He joined the staff in UCLA Medical Center, Los Angeles, CA, Department of Congenital Cardiovascular Surgery before joining and establishing the Fortis Heart Institute and Fortis Healthcare Group. He has performed over 2000 adult and congenital cardiac surgery cases in the past 4 years.

Dr. George Ruiz has joined the adult congenital heart group at Children's. Dr. Ruiz is a graduate of Brown University and the Albert Einstein College of Medicine. He completed his residency in internal medicine at Brigham and Women's Hospital, Boston, and served as chief medical resident. Both during his residency and fellowship in cardiology, he developed an interest in adult congenital heart disease and spent a designated year of training at Boston Children's Hospital under the guidance of Michael Landzberg, MD.

Dr. Joshua P. Kanter has joined the interventional cardiology team. Dr. Kanter recently finished fellowship training in pediatric cardiology and sub-fellowship training in interventional catheterization at Columbia University, Children's Hospital of New York-Presbyterian. Dr. Kanter has research interests in new techniques in the use of intravascular stents, closure devices and balloon angioplasty and the role of MRI in the catheterization laboratory.

And, Dr. Luca A. Vricella will be joining the division of Cardiovascular Surgery in January 2006. Dr. Vricella will direct the Children's Heart Transplantation Program. Dr. Vricella did his general surgical training at The Western Pennsylvania Hospital and The George Washington University School of Medicine. His training in cardiac and thoracic surgery was completed at Loma Linda University and Stanford University School of Medicine respectively. He also completed a fellowship in congenital cardiac surgery at the Great Ormond Street Hospital for Sick Children. Dr. Vricella comes to us from Johns Hopkins, where he has served as the chief of Pediatric Heart and Lung Transplantation and the assistant director of Pediatric Cardiac Surgery.

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CAMP MERIDIAN: SEEK, EXPLORE, DISCOVER

By Naomi S. Gauthier, MD

There are a few experiences in every physician's career that stand out as especially poignant, and become deeply etched in our memories in surprising detail. I remember one such instance, from when I was a cardiology fellow. I sat in a small room facing two young, frightened, and completely overwhelmed parents, and listened as my attending broke the news that their baby had hypoplastic left heart syndrome. The options were outlined as: high risk surgery, await heart transplant, or choose no treatment and let the baby succumb. I remember how powerless I felt, frustrated by our medical shortcomings. I also recall wincing at how much bias crept into the conversation, the experiences of the cardiologist and neonatologist colored their language, the parent's collective background affected their ability to hear clearly, and I had to admit that my own thoughts were slanted. A recent article from Canada reflected on this same slant or bias that affects the care plan chosen.[1] Pediatric cardiology does not have the luxury of large clinical trials, or carefully constructed evidence based medicine. Clinical experience and best judgment is a large part of how we all practice; bias, even if it is for the best, is still an inherent part of this. The positive aspect is that the field remains nimble, creative. It can, and has, advanced at a stunning rate. Flash forward over a decade later, and surgical palliation has become commonplace.

My early experience with that neonate was sharply contrasted by my recent

camp experience with a survivor, a nine year old boy who underwent a Norwood repair. He attended our first ever session of Camp Meridian, a free, non-profit camp for kids with heart defects. This boy, and the other children who attended, taught me to take a long hard look at my own biases, and has given me a fresh new outlook on the practice of pediatric cardiology not just in terms of survival, but in terms of living with their defect.

I founded Camp Meridian four years ago out of the old haunting frustration that modern medicine was not doing enough for these children. We have gotten quite good at diagnosing and treating heart defects, but still lag behind in knowing how to encourage the children to live their lives with a heart defect and not be defined by it. Camp Meridian

was intended to be a highly structured, cooperative adventure to challenge these children to see themselves in a new way, and turn any thoughts of "I Can't" into ones of "I Can." What I did not realize was how much that philosophy applied to the staff as well.

To run Camp Meridian, we rent a beautiful, professional host camp facility on 600 acres in the mountains of New Hampshire. We devise a themed mystery program that transforms camp into a different exotic locale every year. This year we had a tropical theme, entitled "Searching the Sands of Bora Bora." We spent the first afternoon doing get-to-know-you activities, and that evening we gathered around the fire to tell the fictional story of the Tikki Man who gave the power to the Wishing



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Tree, which is a true wishbone-shaped landmark at camp. The story went that a tropical storm came through camp, and blew the Tikki Man's magical possessions away. He lost his armbands (that gave him his strength), his headband (that gave him the power to believe), and his most prized possession, the Tahitian silver pearl necklace (that gave him the power to trust in his heart). The campers then spent the weekend engaged in activities or "missions" which led to clues to find and return the lost possessions. Helping them on their way was the Box of Mystery, a large decorative box that appears every year at camp. The legend goes that it will guide "those who are true and who believe in their hearts." This year the Box produced poems, clues in code, and moti-



ational gifts to point the campers toward their next activity.

Missions have varied through the years, including things like specialized obstacle courses, trying to get a group across a swinging platform without touching the ground, building a working raft while half the team is blindfolded, and the all time favorite, scaling the climbing wall. Creative teamwork is encouraged, and the campers are allowed to figure out solutions without adult interference. As each mission was completed, the children gained a tremendous sense of accomplishment and bonded with their peers in overcoming trials and celebrating shared successes. With excitement mounting to a fever pitch, the weekend culminated with the children digging up buried treasure to find the Tikki Man's lost pearls. One by one, the campers solemnly placed the individual pearls onto his necklace, together rebuilding and restoring his powers. They then received a necklace of their own to keep as a reminder of all that they achieved. To end on a high note, we had a surprise luau celebration, complete with music and food. As the parents arrived, we treated them to a slide show of the weekend's events so they could see with their own eyes their children doing things they may have not thought possible.

Most of these children had never been away from home or slept anywhere other than their own beds. Just attending camp was in itself an accomplishment. We have only two and a half days to develop relationships and give the campers a whole new way of looking at themselves, and I remain amazed at how quickly this occurs. We take time throughout the weekend to reflect on each activity, and each mission group shares with the group at large what elements they used to succeed in their mission, such as teamwork,



respect, and encouragement. The campers are surprisingly frank and open, and you can watch their confidence grow as the weekend progresses. This is helped by our special young adult counselors, who themselves have grown up with heart disease. We have no specified time to discuss heart defects, but invariably the children will decide to discuss their own medical experiences. When the counselors open up about their own heart disease, the looks on the faces of the campers are priceless. They quickly idolize their counselors, and when they find out they too have heart disease, it forces the children to reconcile their images of what it means to have congenital heart disease with what they see in their counselors.

Knowing what these children look like on paper and knowing their medical histories has turned out to be a two dimensional reality when faced with the full scope of what these children can do. This was most apparent to me when I was at the climbing wall. A nine year old boy with hypoplastic left heart syndrome, small for his age, almost dwarfed by the safety equipment, took a deep breath, looked up at the wall, and proceeded to climb all the way to the



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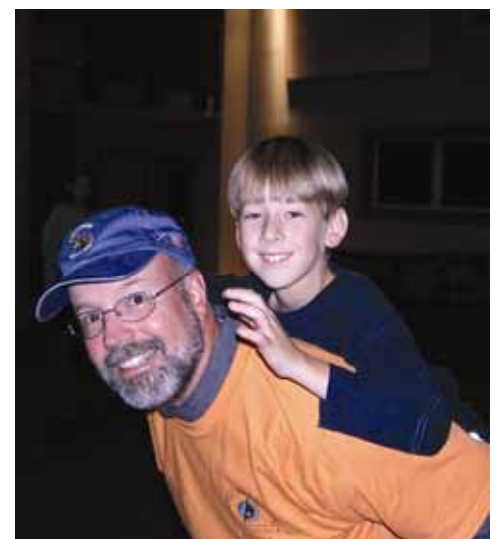
top. His grin at the top, an undeniable accomplishment from his vantage point, made me flash back to the day I listened as the couple chose to take their infant son home to die. Had the boy at the top of the climbing wall been born a few years earlier, his fate may have been different. Had his parents not had the courage to drop him off at camp, he never would have had the opportunity to grin triumphantly from the top of a climbing wall, showing the world that a heart defect is in the eye of the beholder. I then watched a girl, nine years old with single ventricle physiology from double outlet right ventricle and mitral stenosis, approach the wall. She had a fenestrated Fontan and had suffered a stroke at age two years, leaving her with limited use of her left leg and paralysis of her left arm. She made it only a short distance, and slipped a few feet from the ground, caught by the safety ropes. I caught my breath, thinking about how

she was on coumadin, finding myself worrying for no specific reason. I exhaled as I realized how close her feet were to the ground, how safely she and others were guided by the safety ropes, and how little real chance there was for any sort of injury. And this year, the red-headed girl with the Fontan and the left sided hemiparesis, slowly, carefully, and with assistance, made it safely all the way to the top of the wall. It made me wonder about how many times I had guided parents and kids away from activities because they somehow sounded risky, when I probably was acting more from nonspecific parental worry or bias than by any real understanding of kinesiology and pediatric cardiology.

In 21st century pediatric cardiology, we have become very successful at fixing or palliating heart defects. But what about living their lives once the surgery or intervention is complete? We fix their hearts, but what of their self esteem,

their ability to take calculated risks in order to grow, their sense of safety margin that is not overly narrow? We have all seen the effects of the obesity epidemic, and the loss of physical activity in childhood. How do we fairly encourage our patients to have a healthy degree of exercise and a life long commitment to their cardiac health, without encouraging risk? Our adult colleagues have reaped the benefits of cardiac rehabilitation programs in their post-myocardial infarction patients, in what is certainly a higher risk population than most of our pediatric cardiology patients. Although we have some attention made to similar programs in youth, exercise prescription and formal exercise programs are sorely underutilized and we have much to learn.[2-10]

At my town's recreational youth basketball game, I watched my eight year old son and his very competitive, very talented teammate fly down the court and sink a perfect lay up. Both boys have older brothers, and were used to playing with more skilled players. Just a few days earlier, I had read the same boy's



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MRI report confirming increasing left ventricular dimension from his severe aortic insufficiency, and knew that surgery was being recommended. My colleague had not restricted his activities, as he was only eight and this was "rec ball," and common wisdom held that it was "safe." I would have said the same. Sitting in the stands, I had to admit my own inconsistency, as I could see that the intensity of the play was no different from that of my older boys' competitive travel basketball team. This conventional wisdom does have a basis; there is data on workload of different sports,



[11,12] and there are the well-known Bethesda Guidelines.[12] On my review of the literature I could not find any case reports of children experiencing sudden death with exertion before age eight. However, the particulars of competition versus playground play, the skill level of the players, and the individual effort of the patient are harder to pin down, and I think our own biases come into play when we make, rightly or wrongly, the decisions we are asked to make.

"Our motto is Seek, Explore, Discover: seek to be your best and help others, explore yourself and the world around you, and discover the pride of accomplishment and the joy of lasting friendships. The lessons learned transcend congenital heart disease, and are lessons for all."

It remains a challenge to know how to encourage the patients; yet keep within a safe margin; how to allow for personal growth, yet not set unrealistic expectations; and how to avoid risks of obesity and inactivity, yet balance exertional risk. We have a lot to learn from the patients. For two and a half days each fall, when the foliage has reached its peak brilliance in the heart of New England, I am inspired by a group of children whose potential is only just beginning to be tapped. I try to re-learn the very goal we had for these children when we created Camp Meridian: to see that these children are much more than a diagnosis on a page, and that they are,

first and foremost, developing children who happen to have heart defects as one aspect of themselves. One of the many reasons Camp Meridian has been so successful is because of the children themselves. They are remarkably accepting and inclusive; perhaps their own experiences have given them a sensitivity not always seen or encouraged at their age. Watching them blossom has been as deeply meaningful to them as it has been to the staff who supervise the weekend. Our motto is *Seek, Explore, Discover*: seek to be your best and help others, explore yourself and the world around you, and discover the pride of accomplishment and the joy of lasting friendships. The lessons learned transcend congenital heart disease, and are lessons for all.

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“In twenty first century pediatric cardiology, we have become very successful at fixing or palliating heart defects. But what about living their lives once the surgery or intervention is complete?”

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~CCT~

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Camp Meridian

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