The Florida Pediatrician

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Florida Chapter American Academy of Pediatrics

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In this issue.....

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Dear Colleague:

When it is all said and done, the 2002 legislative session will have almost totally ignored Florida's children. As I am writing to you, the budget has not been finalized and despite the numerous indications that our economy is recovering many of the programs important to children and pediatricians remain in serious jeopardy. Funding aside, the legislators could not even pass more traditional "white hat" legislation dealing with child safety, such as seatbelts, booster seats and crib safety, despite claims that deals had been reached for enactment of legislation dealing with many of these issues. It seems that most legislators were more interested in partisan politics and fighting between chambers rather than focusing on the needs of Florida's children. In fact, they couldn't even come to agreement on the critical school code re-write during a session called solely for that purpose!

The entire effort of the Florida Chapter of the American Academy of Pediatrics this session was spent on DEFENSE! We worked hard to kill bills such as Joey's bill (dilated eye exam), and several permutations of the repeal of mandated insurance benefits with the creation of "bare bones" insurance policies. As you know, our chapter has worked for decades to ensure that health insurance policies covered children with special needs. And in one session we were very close to losing it all! Without a doubt, we were successful in defeating these bad bills because so many of you responded to our requests and contacted your local Representatives and Senators on these key issues. Your voice was heard! It made a difference!

* * * * *

...successful...because so many of you responded to our requests..."

* * * * *

Our prime legislative agenda for this year was to streamline the KidCare program by creating a single point of eligibility determination for all programs. A single entry point would begin a process whereby the KidCare program could become a single program for children instead of four separate over-lapping and confusing programs. At this time the concept appears to be still alive but greatly diminished in its scope leaving more work ahead for next year. Despite the dismal showing in the legislature there are many bright spots within the Chapter for which we can be proud. This year members of our chapter received five CATCH grants, including two pediatric resident initiated grants. This outstanding success demonstrates that our members throughout the state are vitally interested in improving the health of our children by developing innovate ways to deliver quality care.

Our annual meeting is coming together very nicely. The program has a set of outstanding speakers including Louis Z. Cooper, M.D., President of the American Academy of Pediatrics.

*(See **President**, page 29 ▸)*

FPIC ad

What Price Our Dignity?

I have written before about the inglorious changes that have befallen us as physicians; e.g., once we had "patients"; then the insurance companies called them "clients" with us as "providers";and now the HMOs have reduced them to "customers". Are we really participants in a retail trade? And now we suffer an attempt to legislate how we may practice pediatrics.

"customers"

Let me hasten to point out that I am neither a zealous conservative nor a zealous liberal. I do not recommend reduction (in the extreme) of government to a giant pork-barrel. Nor do I recommend (in the extreme) a governmental finger in everything in our lives. I do firmly believe in "public health" in apposition to "private health", the former exemplified by neonatal testing, the negative consequences of which impact greatly on the public good and its pocket book.

Now we have faced, repelled, but probably not destroyed an attempt to legislate how we practice medicine, by imposing upon us a questionable procedure with a questionable value. I have great sympathy for the grandmother (and all others) who have suffered the despair of a diagnosis of retinoblastoma in a child. I can almost understand her zeal in seeking legislation for early diagnosis. But, is this a public health problem, which will cost the community untold dollars? Not really. Fortunately, 95% of these infants have a favorable outcome, so that the losses if any are personal and private, not in the realm of public health. And is this the answer to early diagnosis? Not really.

"...how we practice pediatrics."

The bill offered in this session of the Legislature would have required three examinations of the eye, with dilation, before age 6 months. Most pediatricians, though well-trained in eye examinations in children, probably do not have much experience with the neonate. Family physicians do not usually have this expertise. Optometrists (allowed by the bill to do the examination) most likely do not. Most of the examinations would therefore probably devolve upon the ophthalmologists. All this with the increased risk of precipitating glaucoma via the drops at this young age.

Let's look at the other side of the coin. There are approximately 4 millions births per year, in the United States. With an incidence of between 1:14000 and 1:34000 live births, there are about 250 cases of retinoblastoma in the nation per year. Florida, with about 205,000 births, therefore can expect to have 12-13 cases per year. For this, there would be over 600,000 mandated examinations, with dilation, per year. And, since they would be mandated, the state would have to cover the cost. You do the arithmetic on this!

"...our dignity as professionals"

The argument will be made that, if that is what it takes to make the diagnosis, then so be it. Perhaps so, if this were an infallible method and the only one. Actually, experts tell us that the diagnosis can still be missed with retinoscopy, and that it can be readily made, and with at

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*(See **Editorial,** page 29 ▸)*

The Grass Roots

THE REGIONAL REPRESENTATIVES REPORT

(Each month, we provide reports from two of our eight regions)

Region II reports:

The Region II Northeast Florida Pediatric Society has renewed interests and enthusiasm. This has been manifested by increased attendance at our quarterly meetings and by the involvement of our members in a variety of volunteer tasks on behalf of the children of the area.

Our major program, Healthy Child Care/Jacksonville Program, has been extremely active. Steering meetings occur every two weeks. There have been three training sessions and there are now more than 60 active participants who have received training and assignments to serve consultative roles in the daycare centers where they were chosen to participate. This includes more than 40 of the active pediatricians in the area and 20 pediatric residents. In addition, a number of the pediatric resident sub-specialists served liaison roles with the Healthy Child Care/Jacksonville Program and contribute to the resource network that is being created.

We recently established a newsletter for the Healthy Child Care/Jacksonville Program and the first issue was recently published. Jane Veniard who is the coordinator of the Healthy Child Care/Jacksonville Program is also the editor of the newsletter. The feedback that we have gotten from the community, both parents and professionals, has been extremely positive. The doctors who are involved are extremely excited and several have mentioned how much the training has actually helped them in their day-to-day practice roles.

The Healthy Child Care/Jacksonville Program has submitted a number of grant applications. The CATCH Grant that extended from March 7, 2001 to September 7, 2001 funded the initial pilot program. The grant has provided pilot data that is being used in further applications. The program has recently received support from the Jacksonville Children's Commission and from the Kids Care Outreach Program. Several other grant applications have been submitted and are pending. On February 19, 2002, Dr. Robert Threlkel and Ms. Jane Veniard presented information on Healthy Child Care/Jacksonville Program to a group representing childcare advocacy resources throughout the state. This was extremely well received. Dr. Threlkel will present an update on the program at the annual meeting of the Florida Pediatric Society in Orlando. We look forward to your participation in that meeting and welcome your feedback and suggestions. Our area has identified access to mental health care for children as an important problem. Dr. Tajvar Goudarzi has spearheaded the local effort to begin to assist with this problem. She has undertaken, with the help of several of her associates, a catalog of the available resources in the community. We hope to have this published soon. The District Executive Board is also forwarding a pilot needs assessment that Dr. Goudarzi is organizing. From this we would hope to establish a CME Program and speakers to address the needs identified by the pediatric community.

Page 6 *(See **Region II**, page 30 ▸)*

Region III reports:

Many in this district have expressed concern about the national AAP policy concerning homosexual parenting and legalization of gay adoption. Some have expressed support for this issue. How do you feel about this? Is the AAP really representing you and the children you serve? What has the AAP not addressed that they should? What is the AAP doing right? What is the AAP doing wrong?

We are the AAP. I can represent you most effectively if I know what is on your mind. One venue to share your ideas is a town meeting. Before the end of June, we will have a town meeting. Dr. Bucciarelli, President of the Florida Chapter of the AAP will be the guest speaker. Please plan to attend and bring your ideas.

Rosi Fortunato, a member of the search committee to find a new Chairman for the Department of Pediatrics at the University of Florida, stated that the committee was extremely pleased with the large number of highly qualified applicants for the position. After much work the committee has narrowed the field of candidates to seven: Sharon B. Murphy from Northwestern University, James M. Perrin from Harvard University, Peter F. Whittington, M.D. from Northwestern University, Aaron L. Friedman from the University of Wisconsin, Ellen R. Wald from the University of Pittsburgh, Terence R. Flotte from the University of Florida and Richard F. Jacobs from the University of Arkansas. All of these candidates are outstanding. The University of Florida Department of Pediatrics will continue to thrive with whichever of these candidates ends up at the helm.

Dr. Barrett, now the past Chairmen of the Department of Pediatrics, has accepted the position of Vice President of Health Affairs at the University of Florida. I spoke to Dr. Barrett recently about this new position. He said, "I am a pediatrician and will always be a pediatrician first and foremost". Congratulations to Dr. Barrett on his new assignment. We know that he will continue to conduct himself in a way that will benefit children and reflect

[redacted]

Thomas Benton, M.D.
Regional Representative☐

Note:

Visit our society's permanent website at:

[redacted]

for all you want to know about our society, including a summary of The Florida Pediatrician.☐

Note:

Another summary of The Florida Pediatrician is on the website for

the AAP. The URL is:

http://www.aap.org/member/chapters/florida.htm. □

PEDIATRICS 2002- THE UNIVERSITY OF MIAMI SCHOOL OF MEDICINE

R. Rodney Howell, M. D.
Professor and Chairman,
Department of Pediatrics
University of Miami School of Medicine

This is always one of the busiest times of the year with the upcoming graduation of our medical students in early May, and the transition into the new house officers at the beginning of July. Our interns, employees of the Jackson Children's Hospital at the University of Miami, Jackson Memorial Medical Center are selected and supervised by the University of Miami Pediatric Faculty. This year's internship match was one of the most successful in Miami's history, with one of the largest applicant pools we have ever had, from all around the country. We filled from our very top applicants, with a strong representation from the Florida schools, and are very excited about the new year.

The University was very fortunate to have received a multi-million dollar private grant from the Dr. John T. MacDonald Foundation to establish the Dr. John T. MacDonald Foundation Center for Medical Genetics. There has been an extensive search underway during the past year, and the top candidate for directing this center is in final negotiations with Dean Clarkson. This new center, with a focus in Pediatrics, will be across the entire medical school, and bring together the current talent in genetics in both the clinical and basic science departments, but importantly bring to Miami a considerable number of new faculty, staff, and fellows in both clinical and basic genetics. The program will occupy an entire floor in the new Batchelor Children's Research Institute (see below), as well as a considerable space for the genetic diagnostic laboratories in the Mailman Center for Child Development. It is expected that the new Director will be in place by the fall of 2002.

This past year saw the opening of the new Batchelor Children's Research Institute, a magnificent building which brings together the basic and clinical research activities dealing with children and adolescents. This building is privately funded and is named for Mr. George Batchelor who provided the signal gift for the building. Mr. Batchelor, an internationally-known aviation pioneer is the father of a son with cystic fibrosis who was cared for at the University of Miami, and led a productive and successful life well into his 30s. The building is 8 floors and contains 147,500 square feet of research space. The first two floors are dedicated to outpatient clinical research (and parent education) and contain our NIH-funded children's satellite Clinical Research Center. Dr. Gwen Scott, Professor of Pediatrics and Director of the Division of Infectious Diseases and Immunology is in charge of this new unit. The upper floors, some of which are still under design and construction, contains wet laboratory space and small animal facilities. Adjacent to the animal facilities on the 8th floor is a 4.7 Tesla Bruker analytic MRS system that will permit in-vivo metabolic and other research studies on small animals. The building recently won an award for its architects, the Karlsberger Group, from the AIA in Alabama. Karlsberger also recently featured the building at the 2002 International Conference and Exhibition on Health Facility Planning, Design and Construction held in Orlando, Florida in March of 2002. A photograph of the building is shown here. The building faces the Schoniger Research Quadrangle at the University of Miami, which is surrounded by the University's several new research buildings, and provides space for faculty and staff to enjoy the outdoors among very beautiful plantings and fountains.

Batchelor Children's Research Institute, U. Miami

Mr. Batchelor, at the Dedication of the building, surprised the audience by presenting an additional gift of $5,000,000 to establish the Micah Batchelor Research Endowment Fund, in memory of his grandson who was killed in an accident in California just days before the dedication. The income from this endowment is to

(See **Chairmen**, page 30 ▸)

Collaborative Research and PROS

Report

Clinicians from across the United States met in Chicago this last Spring for the biannual Coordinators Meeting. Practitioners from solo and group practices to large university clinics shared insights and concerns about their practice. Research projects relevant to our everyday practice were critically reviewed and some advanced in the pipeline for further development. In practice, it is common to get requests to complete surveys from both academic and commercial sources; not uncommonly the importance and relevance of them is unclear. HOWEVER, PROS studies are reviewed by clinicians and their input helps shape the projects - making them more useful and meaningful to Pediatricians.

In an update from previous columns: the ambitious Life Around Newborn Discharge (LAND) study is entering its final months. The series of surveys describe a mother's and neonate's readiness for postpartum hospital discharge and examines the relationship among maternal, pediatric, and obstetric perceptions & clinical judgement on readiness and health outcomes. A practice in Pensacola, one from Pembroke Pines, and two from Orlando are collecting this information critical to policy makers and the practice of pediatrics. Further a half dozen practices piloted resources developed by the National Initiative for Children's Healthcare Quality (NICHQ) to improve the care provided to children with ADHD. The accomplishments of this collaboration will be shared by the AAP via its new quality improvement program, eQUIPP.

Despite having a network of 1600 practitioners in nearly 600 practices across the country, new practices are always welcomed to join. It takes our participation to ensure the findings of studies will be important and relevant to us. Upcoming PROs studies will test new resources to help busy clinicians promote child safety, aid in child abuse recognition, learn from errors made in ambulatory pediatrics, and better define what goes into a patient visit. If you are interested in partnering at any level (enrolling patients to designing projects), contact us at pros@aap.org or call 800-433-9016, extension 7626. Further, please contact me if you are interested in having a 12 minute slide presentation about PROs at your local hospital or pediatric society meeting.

Respectfully submitted,

Lloyd N. Werk, MD, MPH, FAAP
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Special Article

Your Relationships with Attorneys

One busy Tuesday morning, a nurse knocked on the exam room door to inform me that a sheriff was waiting for me with a subpoena in hand. A lawyer representing a parent of several patients in my practice was demanding my presence in court. The parents were going through a divorce, and, in the lawyer's view, my testimony was needed to help settle issues of custody. The date and time of my court appearance could not have been more inconvenient

In the course of your career in Pediatrics it is likely that you will be obliged to deal with the judicial system on some front. This article is a brief overview of the types of interactions you might experience and suggestions about procedure for these interactions.

Perhaps the most common request encountered is a request for records. When a properly executed request is received from a lawyer for records, you are required to comply. Florida statue provides that you may charge a reasonable fee for this service, and that fee has been determined to be one dollar ($1.00) per page for the first 25 pages, then twenty-five cents ($0.25) per page thereafter (for <u>each</u> patient file). You are permitted to prepare the records and then hold onto them until payment is received. Alternatively, you can send them along with a bill.

Sometimes a lawyer wants your expert opinion (as in the scenario above). In such a case, you are entitled to a fee for your service. You may name your fee for providing this service; I set my hourly rate based on what I would have charged to see patients for an hour. Additionally, the lawyers are often willing to depose you – they can come to your office. A court reporter can create a written record and the proceedings may be videotape for use in court. In this way, you have the potential to provide the testimony at a time and place that are more suited to your schedule.

Finally, you may have the misfortune of being sued or investigated. In such a case, you should not speak to anyone until you have consulted your own lawyer. I have a lawyer on retainer in case such an event occurs. Additionally, your insurance carrier will generally provide a lawyer to represent you.

Returning to the situation above, the lawyer involved was not willing to pay for my professional opinion. My lawyer entered a motion to quash the subpoena, and when the parent's lawyer realized I wasn't going to put up with the nonsense he was

presenting to me, he backed down and paid me for my opinion.

Thomas Benton, M.D.
Gainesville, FL☐

ANNUAL MEETING: See page 21

The Scientific Page

Retinoblastoma

Craig A. McKeown, M.D.
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Introduction

Although very rare, retinoblastoma is the most common intraocular malignant tumor of childhood. In the United States, retinoblastoma develops in about 1 child out of every 15,000 to 23,000 live births. It appears that the frequency has increased somewhat over time. Two hundred and fifty to 350 new cases are identified in the United States each year. Without treatment, retinoblastoma is almost uniformly fatal, however, with early diagnosis and proper treatment, the survival rate is over 90%.[1]

Worldwide, there are an estimated 8,000 new cases each year, of which about 7,000 die from their disease. In the developing world, retinoblastoma commonly extends beyond the confines of the globe at the time of diagnosis. Such cases are usually fatal. The high mortality figures appear to relate primarily to delays in diagnosis as well as a lack of access to expert medical care. In addition to the survival of the child, the survival of the eye itself and the visual capabilities of the affected eye or both eyes, is strongly influenced by the size and location of the tumor(s) at the time of diagnosis.

Much of the credit for early diagnosis and improved survival figures in the United States goes to observant families and their primary care practitioners. It is important for pediatricians to be familiar with retinoblastoma as well as the various ways in which the tumor presents to the family and the primary care practitioner. This discussion will emphasize issues that are important for diagnosis and clinical behavior of retinoblastoma in the primary care setting, rather than treatment by the ophthalmologist or pediatric oncologist.

Genetic Characteristics of Retinoblastoma

Retinoblastoma has provided important insight into our understanding of human cancers, particularly with respect to hereditary cancers and tumor related genes. Tumor suppressor genes were first defined in retinoblastoma and the first human cancer gene to be cloned was the RB1 gene.

Retinoblastoma occurs in both hereditary (germinal) and non-hereditary (somatic) forms. Heritable cases show what clinically appears to be an autosomal dominant inheritance pattern, although the situation at the cellular level is somewhat more complex. Thirty to 40 percent of children with retinoblastoma have the hereditary form of the disease. Most of these represent new mutations, although a few are inherited from a parent who carries the gene, but did not express the gene as a malignant tumor. Only about 6% of new retinoblastoma cases have a family history of the tumor.

About 10% of individuals who carry the mutation for retinoblastoma show incomplete penetrance and therefore do not develop the tumor. A few (<1%) show signs of spontaneous regression of a prior retinoblastoma or "arrested development" in the form of a benign "retinoma". These lesions may be very small and often cause no symptoms or signs, except when indirect ophthalmoscopy is performed by the ophthalmologist.

Laterality is also an important clue to the genetic characteristics of retinoblastoma. The tumor is bilateral in about 30 to 40 percent of cases and virtually 100% of these children have the hereditary form of the tumor. The tumor is unilateral in about 60 to 70 percent of cases and the majority of these individuals do not have the hereditary form of the tumor. However, there are a few important exceptions to this rule. Multifocal unilateral retinoblastoma should be considered hereditary, when it does not appear to be the result of seeding from a single lesion. A solitary unilateral retinoblastoma should also be considered hereditary, when a parent or a sibling has retinoblastoma. In addition, about 15% of children with a solitary unilateral retinoblastoma and no family history of the tumor actually have the hereditary form of the disease, but developed only a single tumor. When first diagnosed in an infant or young child, retinoblastoma may appear to be unilateral. However, over time, tumors may become apparent in other locations in the same eye as well as in the opposite eye, indicating that the individual actually has the hereditary form of the tumor.

The Retinoblastoma Gene

The relationship of retinoblastoma to a specific chromosome became apparent when a few children with multiple congenital anomalies associated with a major deletion in the long arm of chromosome 13 also developed retinoblastoma. Later, the retinoblastoma gene, RB1, was found to be located in region 13q14. Large deletions can be demonstrated by karyotype analysis and all children with a deletion that includes the 13q14 region should be screened for retinoblastoma on a regular basis by an ophthalmologist.[2]

The RB1 gene is rather large, extending over 180 kilobases (kb). It contains 27 exons (active regions responsible for the gene product). The gene product is a nuclear phosphoprotein (p100-RB1) that contains 928 amino acids.

RB1 acts as a "tumor suppressor gene" that appears to arrest the cell's progression through the G1 phase of the cell cycle. For retinoblastoma to develop, both copies of the RB1 gene must be abnormal. If either copy is normal, the cell will not develop retinoblastoma. Thus, at the cellular level, retinoblastoma behaves as a recessive trait, requiring both copies of the RB1 gene to be abnormal. However, at the clinical level, hereditary retinoblastoma behaves as a dominant trait.[3]

In hereditary retinoblastoma, every somatic cell in the body contains one abnormal copy of the RB1 gene and one normal .

*(See **Scientific**, page 25 ▸)*

Special Article

Where are all the Crippled Children?

Steve A. Freedman, PhD, FAAP
Professor and Executive Director
Institute for Child Health Policy
John G Reiss, PhD
Associate Professor and Chief, Division of Program and Policy Affairs
Institute for Child Health Policy

"Crippled children" is a powerful phrase that conjures up pictures of children using wheelchairs and crutches, evoking impulses toward charity and pity. Hospitals and state agencies included crippled children in their names, e.g., Florida Bureau of Crippled Children. That phrase was most popular during the era of polio and its images of iron-lungs and obvious disability and early death.

Those days are gone, as is the standard use of the phrase "crippled children." In the early '70s, the Bureau of Crippled Children changed its name to Children's Medical Services and started calling the kids it served "children with special health care needs." What happened? Parent activism and advances in medical science happened.

The civil rights era spun off empowerment movements for racial, gender, and ethnic groups. The philosophies and techniques of those movements were carefully observed by the parents of special needs children. Even though their numbers were small, parents of these children were no less passionate than their peers in the larger movements.

Two external changes fed the energy of these passionate parents. First were the advances in medical science that gave promise of longevity to their children who, in the previous decade, would have died early in life. Second were the related, but seemingly separate, increasingly complex systems of health insurance, both public and private.

Medicine had conquered polio. The space program supported medicine to understand and apply an array of new technologies related to the functions of human organ systems. Breathing in space seemed important so the respiratory system was one major focus. Flowing from those new technologies were high-tech medical advancements that kept tiny, premature infants alive. Some of those newly surviving newborns came out of neonatal intensive care units with significant health problems, but they lived to go home with their families.

Another leap forward for medical science was the intensive research on molecular biology and human genetics. Understanding more clearly the biological causes of diseases added significantly to the understanding of the biology of the disease process. One of the clearest examples of this advance is the change for children with cystic fibrosis (CF) and their families. In the 1970s, the average age of death for a child with CF was 7 years. Today in industrialized nations, half of the children with CF live to age 31; and in the United States about

one-half of all individuals with CF are age 21 or older.

Many of the children who were surviving did not have the physically apparent disabilities that required crutches - their disabilities were invisible. Those parents rejected the idea and the language that labeled their children as "crippled." Those parents also rejected all language describing the impact of the child's condition, e.g., "handicapped", to a language describing the adaptations required to meet the needs of their children, e.g., "children with special health care needs" and "special education."

These activist parent groups, who began to demand the improvements in medical care for their children, quickly learned that their health insurance did not accommodate their demands. They discovered that the traditions of health insurance focused on covering employees who were adults, and their dependents, which historically included a spouse at home with the kids. Consequently, health insurance benefits were designed for adults, not children, and especially not children with special health care

needs. For example, many health care insurance plans include a benefit called "rehabilitation." An adult who has a stroke might require rehabilitation through speech therapy to restore that function. However, many insurance plans would deny coverage for speech therapy to a child based on the premise that the function - speech - was not there to begin with thus "rehabilitation" was not the service required.

There was recognition at the federal level that these inappropriate traditions of health insurance were not easily adapted to children with special health care needs. However, rather than rethinking the method of insuring the needs of these children, the federal government responded by requiring public insurance (Medicaid) to pay for any "medically appropriate" service. The private health insurance sector has been slow to follow that example. Myriad problems with coverage still remain. For example, in most cases the parents of children with special health care needs are the primary, day-to-day health care providers for their children. These parents provide complex therapies and medications and handle emergencies for their medically fragile children. In doing so they incur out-of-pocket expenses for health care far in excess of those experienced by other parents. None of this is recognized as insured expense.

Another challenge of growing significance is that of transition to adulthood. Until quite recently most of these children with special health care needs didn't reach adulthood.

*(See **"Crippled"**, page 30 ▸)*

Committee Reports

Report of Child Abuse Committee

J.M. Whitworth, M.D.
Jacksonville, FL

REPORT
Child Abuse Committee
Florida Chapter
American Academy of Pediatrics

The members of this committee include:

Neil McWilliams, M.D.
Ingrid Rachesky, M.D.
Lynn M. Keefe, M.D.
Samuel H. Moorer, Jr., M.D
Bruce J. McIntosh, M.D.
Howard L. Rogers, M.D.
Mark Morris, M.D.
Doug Hasell, M.D.
Matthew A. Seibel, M.D
Bill Brooks, M.D.
Kevin J. Foley, M.D.
Jerome H. Isaac, M.D
Katherine Keeley, M.D
Christina Hodges, M.D.
Philip Colaizzo, M.D.
Barbara Rumberger, M.D.
John E. Wright, M.D
Walter Lambert, M.D
Michael Bell, M.D.
Patricia Buck, M.D.
Olga C. Rosa, M.D.
Tom Abrunzo, MD

This committee continues to meet twice yearly in June and October to discuss clinical and administrative issues. It also remains a peer review mechanism for our Child Protection Team Program.

Over the past year the committee has been involved largely in making operational a quality assurance program for multi-disciplinary teams by field-testing the format. This has been accomplished by local site visits by members of the committee and by communicating medical parameters for best practice

guidelines for the Florida Department of Health, Children's Medical Services.

Individual members also serve as Medical Directors of local Child Protection Teams, and close liaisons have been built with the FPS as a whole to assist in legislative advocacy on issues related to child abuse and neglect.

The Florida Chapter has been identified as a resource to assist the AAP in developing recommendations of prevention activities in pediatric offices. The first meeting of this workgroup was held in Dallas this year.

The committee continues to act as a clinical resource to abuse programs and collectively has provided over 1200 hours of training to pediatric and other providers of services to abused children over the past year.

Respectfully Submitted
J M Whitworth, MD☐

Note:

If you are a Fellow of the American Academy of Pediatrics, you are automatically a member of the Florida Pediatric Society/Florida Chapter of the American Academy of Pediatrics, and you automatically receive *The Florida Pediatrician*. If you have not already done so, please pay your annual Florida dues, billed through the Academy Office. ☐

FYI

The AAP will no longer print the tax deductibility disclosure statement on the membership dues invoice. Since we are incorporated as a 501 (c) (6) organization, we are required by the IRS to notify our members of the amount of dues that can be deducted as a business expense:

Dues remitted to the Florida Chapter are not deductible as a charitable contribution but may be deducted as an ordinary necessary business expense.

However, 30% of the dues are not deductible as a business expense for 2001 because of the chapter's lobbying activity.

Please consult your tax advisor for specific information.☐

Managed Care

HMOs and Managed Care - Apoptosis for Medicine

Lewis A. Barness, M.D.
Professor of Pediatrics
University of South Florida College of Medicine

[This article originally appeared in May of 1996. In the ensuing time, its wisdom has remained intact, and it is therefore repeated!]

Note:

The Florida Pediatrician has had and continues to have a policy to print an article on Managed Care in each issue. This policy will be adhered to so long as suitable articles are submitted. Both sides of the issue will be represented.

Publication of an article does not indicate any endorsement of the opinion by *The Florida Pediatrician* or by the FCAAP/FPS.☐

Healthy children are the foundation for a mentally and physically competent adult population. Optimal health care for children includes prevention of most illnesses and easy access to treatment of diseases in their earliest and least devastating stages. The physician's natural role includes prevention of diseases through recommendations for good nutrition, spacing of births, avoidance of recognized detrimental health habits, provision of immunization against susceptible diseases, and others. The physicians' unique rôle is in the treatment of ill patients. Requirements beyond the primary expertise of physicians include a salubrious psychosocial and physical environment. The costs of the latter have often been included in calculations of the cost of health care.

In the haste to lower costs, maintenance of health has been given a subservient position in the development of HMOs and "alleged" managed care. The intrusion into a system for health of the priority for lowering costs is itself inimical to delivery of health care. However, certain components of many of the HMOs appear logical and beneficial. Preadmission certification for hospital admission, early hospital discharge planning, second surgical opinion and quality assurance review appear to be worthwhile practices developed by HMOs. Some have introduced "smart cards" which carry patient medical histories. These components deserve adoption by all. Some of the HMOs are thus excellent models. Among these, not-for-profit organizations are more often found than those for-profit. Ambulatory care groups, group teaching sessions and case management for children with complex medical problems are other examples of efficient practices.

Other practices appear divorced from health maintenance. Preauthorization of services, predetermined limits for the use of services, capitation, risk pools and "withholds", and limitation of direct access to specialist care are decisions often made by unqualified individuals. Physician incentives to reduce use, the limited availability of services, biased selection of enrollees, limited selection of physicians, and other characteristics are likely to inhibit good patient care. Restriction of discussion of treatment alternatives or the practices of some organizations is a horrendous insult and has required back-tracking by some companies.

In a limited number of studies, statements have been made that costs and death rates are decreased. In other studies, total costs have not risen but health has decreased. Much of the patient costs has been taken from health care to provide advertising for organizations, inordinately high salaries and bonuses for CEO's and others not involved in health care, and complex administrative expenses. Simultaneously, compensation to physicians has decreased and their expenses, especially those related to the complexities of paper work for billing multiple companies with multiple requirements, are increased.

Most importantly, no funds are allocated to medical education. Funds for research are non-existent. Even compensation for clinical research is minimal. Teaching hospitals are discriminated against because of cost, and medical schools are finding decreasing opportunities for innovation, to the detriment of students. Superficiality is becoming the mode of primary care gate keepers, who are obligated to provide the least expensive care possible. The present morass should be improved.

First, HMO's should be renamed "Medical Business Companies" (MBC). MBCs more accurately describe their existence and operating procedures.

Next, a single payor with universal coverage would eliminate a number of problems associated with the MBCs. The entire population would have access to care, paperwork would decrease, access to records would be facilitated, medical decisions would once again devolve on physicians, physicians would compete less with physicians so that a sensitive doctor-patient relationship could return. Case management for those with complex medical problems would assist in providing efficient care. Ombudsmen should be available for complaints. A logical definition of malpractice should emerge.

A single payer, likely the federal government, is not without problems. Funding is not inexhaustible and rationing may become necessary. A two-tier system would probably emerge and some "pay for services" may result in limited private practices. Deductibles may be instituted to avoid excessive or unnecessary usage. Very expensive services, such as those for very small newborns as well as for the terminally ill, may have to be limited. Interventions that are of little value would be discouraged while those that are effective, cost effective and beneficial would be encouraged. Self-injurious practices would become the responsibility of the individual.

Changes are on the horizon as evidenced by the number of states considering legislation and regulations. It is appropriate that physicians assume primary responsibility for developing more rational and improved health care delivery systems. No one system can possibly satisfy everyone, but decisions should provide the greatest good for the greatest number.

Ed. Note: apoptosis (ă-pop-to'sis, ă-po-to'sis)[G. a falling or dropping off, fr. apo, off + ptosis, a falling] Programmed death.☐

ANNUAL MEETING: See page 21

From the Resident Section

Laura P. Stadler, M.D.
Chief Resident, USF Residency Program

[In each issue, we will focus on the State's Residency Programs or on issues affecting all progams.]

Residents representing the state of Florida met March 15-17th in Orlando with Districts 2 and 5. In addition, the district representatives met April 19-21st in Chicago, IL for the Resident Section of the AAP.

Florida is unique in that the AAP Chapter supports its residents in SO many ways. Residents' annual membership of AAP is provided by Florida residency programs to encourage their participation in the academy both in residency and in the "real world". In addition, members of theAcademy support our actions by providing funding for monthly teleconference calls (among programs in the state and district) for our advocacy programs and support. This is not widespread nationally when talking to other residents at other programs! We truly appreciate the support and mentorship that Florida Pediatricians offer, including the opportunity to have a voice in this newsletter!

District X (FL, GA, AL, and Puerto Rico) chose the advocacy topic of "Increasing Physical Activity/Decreasing the Obesity Epidemic" for this year. Ways to implement this during residency include:

- Present a noon conference regarding not only statistics of the obesity "epidemic" among children, but ways (even if they are small) to implement them in clinics, practice of pediatrics. This may be done by a resident, chief, or attending.
- Add questions to Well child care visits regarding diet, exercise, high risk factors such as: family history of cardiovascular disease of early onset (MI prior to 50), presence of TV in bedroom, # hours of tv/videogames per day.
- Make handouts for patients and families for various age groups: infancy, preschool, school age, adolescent, special diet groups (vegetarians).

Suggestions for handout materials include:

- D/C soda: switch to diet soda, Crystal light, water.
- Eat 3 meals a day
- 6-8 glasses of water/day
- 3-5x/week of 30 minutes of aerobic exercise (walking, biking roller blading, swimming, sports).
- Remove TV from children's bedrooms
- Restrict TV viewing, video games
- Encourage play outside: parks, gyms, YMCA, Boys/Girls Clubs
- GET INVOLVED! in extracurriculars/sports at school, church, neighborhood

Perform Physicals and identify children who are obese or at high risk:

- Schedule followup visits for those at high risk and monitor their progress/setbacks
- Sponsor fairs at school, neighborhood to encourage healthy eating habits, exercise, involvement
- Adopt a class/grade at a local school
- talk to teachers, PE teachers, students
- Ask about curriculum for PE: Is there actual physical activity or time spent reading about it?
- D/C coke machines from schools
- Examine the menu at schools: Talk to administrators, teachers regarding the amount of FRIED food served to children
- Consider support groups, exercise groups, "Buddy" system for exercise and healthy eating habits
- Consider an obesity clinic: once a month with a nutritionist available for patients
- Concentrate on FAMILY: children often adopt parents' lifestyles; nutrition consultations for the family with meal planning.
- Consider implementing recommendations in your residency program's advocacy time/month to focus on how pediatricians can best counsel and support children with obesity.

Other resident information:

CATCH grants are available for download from the AAP website. This is an excellent opportunity to support an advocacy goal. In addition, medical students aspiring to become pediatricians may participate in a CATCH grant with a resident or other mentor. Consider doing this in your community.

Don't Forget !!

Suncoast Conference is June 14-15th at St Pete Beach

The Florida Chapter of AAP conference is June 21-23rd. It is FREE to residents! Dr Sinclair will be speaking at the resident meeting on June 22nd re: "Common Sports Injuries in Children" Please make plans to attend!

Any comments or suggestions regarding the resident section of the Florida AAP, please contact lpstadler@hotmail.com. ☐

MEMBERSHIP ALERT!

Do you know any pediatricians, Fellows of the Academy or not, who appear to have been overlooked by the Society, and are therefore not members? Contact the Executive Vice President or Membership Director. There are several kinds of membership in the Society:

Fellow: A Fellow in good standing in the American Academy of Pediatrics - automatic membership on request.

Member: A resident of Florida who restricts his/her practice to pediatrics.

Associate Member: A physician with special interest in the care of children.

Military Associate Member: An active duty member of the Armed Forces stationed in Florida and limiting practice to pediatrics.

Inactive Fellow or Member: Absenting self from Florida for one year or longer.

Emeritus Fellow or Member: Having reached age 70 and having applied for such status.

Affiliate Member: A physician limiting practice to pediatrics and in the Caribbean Basin.

Allied Member: A non-physician professional involved with child health care may apply for allied membership.

Honorary Member: A physician of eminence in pediatrics, or any person who has mede distinguished contributions or rendered distinguished service to medicine.

Resident Member: A resident in an approved program of residency.

Medical Student: A student with an interest in child health advocacy.☐

[The Florida Physicians Insurance Company (FPIC) is endorsed and sponsored by the Florida Chapter of the American Academy of Pediatrics as its exclusive carrier of malpractice insurance for its members. In each issue, FPIC will present an article for our readers on matters pertaining to risk management]

Physician Practice Sample Risk Management Plan

Cliff Rapp, LHRM
Vice President Risk Management, FPIC

Each physician office is committed to providing quality care to patients. This includes protecting the safety and dignity of patients, providing qualified staff, coordinating care with attending physicians, and maintaining financial stability. Every practice should have a risk management plan, which is a process whose goals are to identify and minimize risk exposures within the ambulatory environment, to respond to claims or suits in a manner that will minimize financial loss, and to achieve patient and family satisfaction. Employees and attending physicians should work together to achieve these goals.

Clinic management retains the ultimate responsibility for the effectiveness of the risk management plan. It is recommended to appoint an individual to be responsible for risk management issues who:

identifies risk exposures within the environment

maintains a risk reporting system for the purpose of identifying adverse occurrences and potentially compensable events

trends risk management data and reports to clinic administration

maintains an integrated relationship with the facilities in which the group provides care

plans and implements risk reduction initiatives

provides risk management education to employees when appropriate

secures adequate risk financing

utilizes risk management data only for the purpose for which it is intended

assures that confidentiality is consistently observed

A method of risk management reporting should also be developed. It includes the purpose of reporting; who, what, when, and how to report; confidentiality; event investigation; event follow-up; report distribution; and medical records documentation.

Once an occurrence is reported, a supervisor, the risk manager, or other designee may investigate the event. The investigation should include interviews with all those who witnessed or were involved in the occurrence. A detailed description of the scene and any missing items should be included. The investigation contains a report to the patient's physician, family, and other healthcare professionals as indicated. Any follow-up actions taken to evaluate the patient's condition and/or correction of identified hazard should be included as well. It is most important that the investigation include a reporting of potentially compensable events to the professional liability carrier.

An occurrence trending and analysis program should also be implemented as part of the risk management plan. Such a program includes classification and counting of similar events, such as medication errors, patient complaints, etc., and reporting data to the group responsible for its review and evaluation.

The office administration or their designee will report patient and/or family complaints alleging injury, dissatisfaction, or legal action to the liability insurance carrier. A file for each such allegation is maintained in a confidential manner. Full cooperation with the carrier claims handler will be effected.

All employees should be oriented to the risk management program and their roles in the program within 30 days of becoming employees within the practice. The orientation will include, but not be limited to, occurrence reporting, patient safety, and patient/family relations. In addition, an annual program on risk management topics should be provided. Special presentations tailored to address specific problem topics may be scheduled as needs arise.

The key to avoiding claims is to have an office risk management plan. Such a plan can be used to track errors and identify potential areas that need improvement before a claim arises.

[Information in this article does not establish a standard of care, nor is it a substitute for legal advice. The information and suggestions contained here are generalized and may not apply to all practice situations. FPIC recommends you obtain legal advice from a qualified attorney for a more specific application to your practice. This information should be used as a reference guide only.]□

ANNUAL MEETING: See page 21

Aventis ad

KEEP SKIN SAFE AND HEALTHY ON SPRING BREAK

[This release from the AAP was issued in advance of Spring Break. However, it is appropriate in Florida almost all year round. Although Floridians are not the ones who sit in the sun, our children still are, and this warning is appropriate for them . -Ed.]

CHICAGO - Spring break time is here, and that means it's time for hundreds of thousands of young people to visit beaches and local tanning salons. But whether the tan comes from a salon, or the sun, young people are not doing their skin any favors.

The American Academy of Pediatrics (AAP) wants to warn high school and college students that chronic sun exposure eventually can cause signs of premature aging - including wrinkles, sagging cheeks and skin discoloration.

The AAP also says that long-term sun exposure is a key factor in the development of skin cancer. Most "non-melanoma" skin cancers (the most common cancer in America) are caused by unprotected sun exposure in childhood and adolescence -- specifically ultraviolet or "UV-A" and "UV-B" rays. Research shows that bulbs at tanning salons emit ultraviolet rays too. Sophie J. Balk, MD, FAAP, chair of the AAP Committee on Environmental Health says, "There is really no such thing as a safe tan - all tans cause skin damage."

The deadliest form of skin cancer, called "melanoma," killed about 7,800 people in the United States last year, and that number is expected to rise this year. Melanoma often strikes people who suffer deep, intense sunburns, particularly in childhood and adolescence.

But it's not too late for high school and college kids to prevent further damage to their skin - and they don't have to give up their spring break fun either. Just remember these tips:

- The first, and best, line of defense against the sun is covering up. Wear a hat with a three-inch brim or a bill facing forward, sunglasses (look for sunglasses that block 99-100% of ultraviolet rays), and cotton clothing with a tight weave.
- Stay in the shade whenever possible, and avoid sun exposure during the peak intensity hours - between 10 a.m. and 4 p.m. The risk of tanning and burning also increases at higher altitude.
- Sunscreen with an SPF (sun protection factor) of 15 should be effective for most people. Be sure to apply enough sunscreen - about one ounce per sitting for a young adult.
- Reapply sunscreen every two hours, or after swimming or sweating.
- Some self-tanning products contain sunscreen, but others don't, so read the labels carefully. In addition, tanning oils or baby oil may make skin look shiny and soft, but they provide no protection from the sun.☐

Pediatrician Referral Service

To assist parents in their search for a pediatrician, the American Academy of Pediatrics on March 1, 2002 had the initial launch of the Academy's Pediatrician Referral Service (PRS). The PRS is a public version of our Fellowship Directory. The Academy has, for many years, been fulfilling referral requests from parents by forwarding information from our Directory.

By putting this service online, we expect more parents to make use of it, and as a result, more pediatricians to gain new patients. It will provide families with an opportunity to locate pediatricians by State, City, and/or Zip Code and to doso when it is most convenient for them. The PRS will be accessible on the AAP Web Site, www.aap.org, and will draw from the information our members list as their "Fellowship Directory Address."

If you do not provide a Fellowship Directory Address/Pediatrician Referral Service Address, your Preferred Address will be used for the Pediatrician Referral Service. Considering this, you may want to provide a Fellowship Directory Address/Pediatrician Referral Service Address.

If you would like to change the address that is used for the Fellowship Directory and the Pediatrician Referral Service you can do so by logging onto the Members Only Channel and clicking on the "View my Personal Link" in the left-side navigation bar.

Participation in the PRS is optional. We hope that all AAP members will choose to participate, however, members who choose to withdraw their names can do so by contacting the Division of Member Services at 800/433-9016.☐

MMR Vaccine and Autism

The first in a series of conferences around the country takes place this weekend in Pontiac, Michigan, when Dr. Andrew Wakefield is expected to further promote his controversial claim of a link between the MMR vaccine and autism.

To ensure AAP members in all chapters have materials to counter any publicity resulting from Dr. Wakefield's appearances, we have posted materials on the Members Only Channel (MOC) of the AAP Web site. Titled "MMR and Autism Resources," the materials include a list of Frequently Asked Questions, a backgrounder, a sample letter-to-the-editor, and links to other Web sites that contain information and studies on MMR and autism. Many of these documents will also be posted on the public side of the AAP Web site this week.

Please note that we do not want to help generate publicity for Dr. Wakefield and his unsupported theory, but our members should be prepared in the event they are contacted by the media. Feel free to notify your chapter members that this information is now posted on the MOC.

Conference dates are:

April 13-15: Pontiac, MI
April 23-26: Wilkes-Barre, PA
May 10-11: Boston, MA
June 1-2: Dallas, TX
July 17-21: Indianapolis, IN
Oct 25-27: San Diego, CA

Joe M. Sanders, Jr., MD☐

FDA Suspends Drug-Testing Rule

March 18, 2002
WASHINGTON (AP) - The Food and Drug Administration is suspending a rule that lets the government require safety testing of adult medicines commonly given to children - from asthma treatments to Prozac.

The reason: FDA says Congress recently reauthorized financial incentives for manufacturers to do those studies. The FDA said it wants to see if the new law akes the old mandate, which drug makers hated, unnecessary.

But three Democrats complained to President Bush on Monday that the action was halting "an important regulation that protects children from potentially unsafe and improperly dosed medications."

Adult medications are commonly given to chldren without studies of their safety or proper dosing because doctors have no alternative.

Drug makers have used the financial incentives to focus their studies on more expensive drugs, like Prozac, rather than cheaper ones that no longer have patent protection, but are used as much if not more in children, wrote Reps. Henry Waxman of California, John Dingell of Michigan and Sherrod Brown of Ohio.

The FDA's so-called "pediatric rule" was adopted in 1998. A conservative think tank and the Association of American Physicians and Surgeons immediately filed suit against it, represented by an attorney recently appointed to be the FDA's chief counsel. He reportedly has recused himself from the government's debate of the issue.

Shortly after the pediatric rule's adoption, Congress passed the financial incentives, so it's unclear towhat extent the FDA ever forced manufacturers into child drug studies.

The Best Pharmaceuticals for Children Act, signed into law in January, reauthorized the financial incentives, plus set uup a grant program to allow taxpayer dollare for pediatric studies of drugs their makers, despite the incentives, won't do.

During a two-year suspension of the older mandate, the FDA will assess if the new law takes care of the problem said spokeswoman Susan Cruzan.

But the new law is "no substitute for requiring drug makers to perform safety studies," said Waxman spokeswoman Karen Lightfoot.

While the suspension is scheduled to last up totwo years, "our intention is to resolve this issue quickly to ensure that children's medications are safe and used properly," the FDA said in a statement late Monday.

Deborah Mulligan Smith□

World Congress on Drowning

The World Congress on Drowning is going to be held in Amsterdam June 26-28, 2002. This is the first time an international conference has been held to specifically look at drowning rescue, prevention and treatment.

World-wide half a million people die each year due to drowning. Drowning knows no geographical boundaries and in the ages of 5 to 14 is actually one of the leading causes of death. To date no concerted action has been established regarding global drowning issues. Consequently, the World Congress on Drowning will be a unique event for experts, organizations and institutions involved in water safety.

For more information, including the preliminary program, visit the website link at: http://www.drowning.nl

Florida 7-year study is being presented at this meeting.

Deb. M. Smith

F.Y.I.

ACIP Recommendation on Hepatitis B

In January, the CDC, through the Advisory Committee on Immunization Practices, published its Recommended Childhood Immunization Schedule - United States, 2002 (the "harmonized schedule") in the MMWR. This schedule is in the hands of all practitioners, either from CDC or from the American Academy of Pediatrics, a major member of the "harmonized group".

There is an important suggestion noted in this report: The schedule indicates a preference for administering the first dose of hepatitis B vaccine to all newborns soon after birth and before hospital discharge. This contrasts with an earlier suggestion that the first dose be delayed to a later visit.

Administering the first dose of hepatitis B vaccine soon after birth should minimize the risk for infection because of errors in maternal hepatitis B surface antigen (HbsAg) testing or reporting, or from exposure to persons with chronic hepatitis B virus (HBV) infection in the household, and can increase the likelihood of completing the vaccine series. Only monovalent hepatitis B vaccine can be used for the birth dose. Either monovalent or combination vaccine can be used to complete the series. Four doses of hepatitis B vaccine, including the birth dose, can be administered if a combination vaccine is used to complete the series.

In addition to receiving hepatitis B immune globulin (HBIG) and the hepatitis B vaccine series, infants born to HbsAg-positive mothers should be tested for HbsAg and antibody to HbsAg (anti-HBs) at age 9-15 months to identify those with chronic HBV infection or those who may require revaccination.□

Make A Wish Foundation of Southern Florida

As a health care provider, you play a major role in our community. It is at this time that we are being called to participate in the most noble of causes, to grant a child with a life-threatening illness the lasting experience of one most precious wish. Make A Wish Foundation of Southern Florida has granted nearly 4,000 wishes in the past 19 years. However, much more still needs to be done to reach eligible children so that they too can receive their once-in-a-lifetime wish, and you can help.

The Health Care Advisory Meeting was created as a nesting place for increasing the amount of children that can be empowered by the granting of a wish. The most recent meeting was held this past February 11, 2002 in Fort Lauderdale Airport's Sheraton Hotel with Make A Wish Board Members and over 15 distinguished members of the health care community. Among the hospitals and societies represented at the meeting were the following: Joe DiMaggio's Children's Hospital, Broward County Medical Association, Pediatrix Medical Group, The University of Miami and Palm Beach County Medical Society.The purpose of getting more referrals of children to Make A Wish is simply that more lives can be touched by the "power of a wish".

The true meaning of granting a wish is giving a child with a life-threatening illness the opportunity to take control over his/her destiny. This seemingly unlimited power serves to distract the child from his/her condition, encourage them to pursue their dreams, and, ultimately, to pursue life.

However, each time we fail to serve eligible children, all the chances of accomplishing these goals are gone. Often times Make-A-Wish has seen critical medical conditions improve dramatically after a wish was granted. It is a shame that so many children still remain untouched by a wish that Make-A-Wish wants to grant only due to improper communication. Although, we are pleased to see how medical improvements many times account for the decrease in the amount of children referred to the foundation; it is unfortunate that these numbers sometimes reflect a decrease because medical caregivers are unaware of the possibility of referring children with only life-threatening illnesses.

Additionally, Make-A-Wish is also limited by the negative views that the families of ill children have about their services. Too many of these families mistakenly believe that they are dedicated to giving a child his/her "last wish", as if to let him/her die happily. The reality of Make-A-Wish's mission is, in fact, the complete opposite; they are there to promote life, they are there to encourage a child and his/her family, they are there to give a child the "power of a wish".

By referrng children and learning more details about Make-A-Wish, you are actively working to improve the amount of children who experience this life-changing dream. Gradually, but steadily, you can help Make-A-Wish increase the number of children in the Tri-County Area of Miami-Dade, Broward and the Palm Beaches, that get the joy and hope of a wish.

For more information regarding Make-A-Wish, call: (954) 967 9474 or visit www.wish.org/southernfla. ☐

New OSHA Requirements Help Protect Healthcare Workers from Dangerous Needlestick Injuries

With 5.6 million healthcare workers impacted by the Occupational Safety and Health Administration (OSHA) regulations, these individuals are inherently at risk for needlesticks that may lead to potentially chronic or fatal diseases, including hepatitis B, hepatitis C and HIV. Approximately 800,000 needlesticks occur annually, with approximately 47 percent of hospital injuries affecting nurses, 13 percent physicians and 24 percent other healthcare workers such as technicians and attendants. The National Institute for Occupational Safety and Health estimates that as many as 88 percent of needlestick injuries can be avoided with the use of safer medical devices, including needles.

That is why OSHA recently revised its bloodborne pathogens standard, effective April 18, 2001 and enforced beginning July 17, 2001 mandating that all healthcare facilities provide safer medical devices, including needles, as they become available, and document all injuries incurred from contaminated needles, not just those that lead to illness. If healthcare facilities do not use safer medical devices, they must explain why in their annual exposure control plans or risk fines of up to $70,000.

"As a nurse, I know first-hand that needlestick injuries can cause serious physical, emotional and financial damage to healthcare workers and their families," said Barbara DeBaun, Director of the Infection Control Program at California Pacific Medical Center in San Francisco, California. "Hospitals and other healthcare facilities now need to do their jobs and provide safer needles that will reduce the risk of needlesticks in their workers."

When a healthcare employee is stuck by a needle, the cost of prevention, diagnosis and treatment per worker can range anywhere from $500 to $3,000 annually. The General Accounting Office estimates that healthcare facilities can save up to $173 million yearly by helping to prevent needlesticks.

The U.S. Food and Drug Administration recently approved GlaxoSmithKline's Safety Tip-Lok™: prefilled Tip-Lok® syringes packaged with BD SafetyGlide™ Needles for pediatric doses of Havrix® (Hepatitis A Vaccine, Inactivated) and Engerix-B® [Hepatitis B Vaccine (Recombinant)]. *Havrix* and *Engerix-B* are the first and only pediatric vaccines available with *Safety Tip-Lok*, an all-in-one delivery system, which meets OSHA's newly revised bloodborne pathogens standard. Other systems are sure to follow.

As of July 17, hospitals and medical offices across the nation are required to exercise compliance or face hefty fines and citations. Employers must take responsibility to make sure that employees have access to safe needle devices – after all, it's the law.

For more information about needlestick safety and prevention, visit www.osha.gov or www.cdc.gov.☐

The *Ticked Off* Column.

If you are really "ticked off" about something in your practice or about medical economics in general, write about it and send it in. Any reasonable complaint will find its way into print!☐

Deise Granado-Villar, MD, MPH, FAAP
CATCH Co-Facilitator
Florida Regions V-VIII

Progress continues to be made by Florida's recipients of CATCH planning grants on their efforts to improve access to quality health care to all the children of our State.

The expansion of the Growing Healthy Network Project led by Dr. Ana Maria Hernandez-Puga, Medical Director of the Primary Care Clinic of the Children's Diagnostic & Treatment Center in Hollywood, Fl continues. This project is aimed at identifying barriers inhibiting families in high-risk areas from access health care for their children, and to establish a pathway for these children to access and utilize a medical home. The 2000 CATCH grant was highlighted by a detailed assessment of the health needs of the population of children targeted by this project, forging community collaborations and partnerships, and by the involvement of grass roots groups.

CATCH funding has been essential and instructive in determining places in our community where health care for children is most needed. The Children's Diagnostic & Treatment Center has recently relocated a satellite clinic, serving children with special health care needs, as a result of this grant", said Dr. Hernandez –Puga. Continuous funding opportunities for this project are being pursued through grants by the United Way Success by Six program, The Florida Department of Health, The American Academy of Pediatrics and the Federal Department of Maternal and Child Health in partnership with the Broward School Readiness Coalition and a local agency for subsidized child care.

Another exemplary 2000 CATCH effort is the BABY SO SOON Project awarded to Dr. Gloria Riefkhol, Director of School Health, Department of Preventive Medicine and Community Pediatrics at Miami Children's Hospital. This project was designed to assess the skills of Hispanic teen mothers in caring for their newborn infants, and their basic knowledge of common health issues such as fever, feeding problems, use of child safety devices, and others. An educational curriculum was designed based on a direct face to face interview of 200 first time teen mothers ages 10-19 years of age. The importance of primary and secondary prevention of pregnancy, early access to pre-natal care, as well as the role of a medical home in healthy child growth and development, was emphasized through the curriculum.

The BABY SO SOON Project has increased collaborations with the Adolescent Pregnancy Prevention and Parenting Council of Miami-Dade, the local Department of Health, the school system, Healthy Families and Healthy Start, and local subsidized child care centers. Secured funds for this project have been received from the March of Dimes, and other supporting agencies for continuation of this effort.

CONGRATULATIONS to these two "winners for children" for taking an active role in making a difference for our children.

As a reminder to all, applications for the CATCH Rome Community Access to Child Health (CATCH) Visiting Professorships in Community Pediatrics for 2003 will be mailed during the month of May. The program provides four accredited pediatric residency programs up to $4,500 each to fund a three-day educational program focusing on the field of community pediatric to promote advocacy for children and advance the field of community pediatrics. This program was established in honor of Leonard P. Rome, MD, a pediatrician and tireless child health advocate, who dedicated his life to improving children's health. Dr. Rome's life exemplified the vision of the CATCH Program - that every child in every community have a medical home and other needed services to reach optimal health and well-being. Please take advantage of this opportunity.

Our most expressive appreciation goes to the Department of Community Pediatrics of the AAP, and to all who make funding of CATCH initiatives possible.□

ANNUAL MEETING: See page 21

SAVE THIS DATE

June 21 - 23, 2002

General Pediatric Update VIII

and

Florida Chapter AAP
Annual Business Meeting

National Speakers include:

David Skoner, M.D.
Department of Allergy/Immunology
Children's Hospital of Pittsburgh

Joseph E. Dohar, M.D.
Pediatric Otolaryngologist
Children's Hospital of Pittsburgh

David B. Granet, M.D.
Pediatric Ophthalmologist
Shiley Eye Center, University of California - San Diego

Also: Alumni Meetings will be held for the Florida Pediatric Alumni Association, Inc.,
University of Miami/Jackson Memorial Hospital Pediatric Alumni
University of South Florida Pediatric Alumni
APH Pediatric Alumni Association, Inc.

Location: Grosvenor Hotel
Lake Buena Vista, FL
Call early for hotel reservations, at 1-800-624-4109
(Mention Florida Pediatric Society block of rooms!)

(CME Credit Available) (Registration details later)

National Early Hearing Detection and Intervention Program

Thomas L. Truman, M.D.
Florida Pediatric Society (FCAAP), EHDI Chapter Champion
Tallahassee, FL

As a Chapter Champion on early hearing detection and intervention, I would like to share some very important information with you. I recently attended the National Early Hearing Detection and Intervention (EHDI) meeting in Vienna, VA and learned so much about how very important this issue is in pediatrics. At this meeting I met with many others in our state who are working on EHDI issues – including audiologists, early interventionists, and parents of children who are deaf or hard of hearing.

Perhaps the most moving session was the presentation given by a mother of two children with hearing impairment. Her story was particularly poignant as she experienced many obstacles and frustrations with medical professionals when she was initially concerned about her first child's hearing. It took nearly two years to definitively identify her child with a hearing loss that she suspected for some time. The well-meaning, but "wait and see" approach is a common story I have heard from many families. For this family, the consequences of the delayed identification of their first child was magnified by the birth of another sibling with hearing loss and early identification and intervention. The comparison of language differences between her two children was marked and speaks quite clearly to the critical importance of early identification and intervention for children with hearing impairments.

As pediatricians we need to know that an infant with hearing loss may present in our office and respond to environmental sounds and even our spoken voice, depending on the type of loss, the degree of loss and the frequencies affected. Such responses only confirm that hearing loss is truly an invisible disability. Even mild losses may impact speech and language learning. Physicians should listen carefully to parents who express this concern.

As you may recall, in 1999 the American Academy of Pediatrics published a policy statement entitled, *Newborn and Infant Hearing Loss: Detection and Intervention*. This policy statement highlights the Academy's recommendations in support of universal newborn hearing screening and can be found on the Academy's Web site at http://www.aap.org/policy/re9846.html. More than two-thirds of the states have passed legislation mandating universal newborn hearing screening; however, this legislation is seldom ideal in terms of providing optimal benefits for children and families. In the 2000 legislative session, Florida joined the growing number of states mandating newborn hearing screens with Florida statute 383.145. This statute requires licensed hospitals and birthing facilities to screen all newborns for hearing loss prior to discharge if the parents do not object. While this has clearly been a positive step toward identifying newborns with hearing loss, there remains more work to be done in terms of ensuring that appropriate interventions (and funding for interventions) are utilized and services available for those diagnosed with hearing loss.

I would like to offer a brief overview -- in the form of a Q&A -- of the physician's role in the follow-up of infant who did not pass newborn hearing screening. I hope you will find this information useful in efforts to gain a common knowledge base for moving forward.

Question: What should a primary care physician do if a newborn doesn't pass the hospital-based hearing screening?

Answer: It is important to understand the prevalence of newborn hearing loss and the accuracy of initial hospital screening. If a newborn is never screened before hospital discharge, the child has one in 650 chance of having an undetected congenital hearing loss. But, depending on the screening test used, the child who fails the initial screening may have a risk of confirmed hearing loss as high as one in 10! It is reasonable to reassure families that their own child may be shown to have normal hearing, but it is critical that every newborn who fails initial screening return for follow-up screening and confirmatory testing if indicated. This may be a joint responsibility shared with the hospital and/or the audiology department, but nothing is as powerful as a phone call from the physician if for any reason the child has not returned in a timely manner.

Question: When should the infant be rescreened?

Answer: Infants should return promptly for rescreening – within the first few weeks of life. The infant should complete rescreening and confirmatory testing quickly so that if a hearing loss is identified, early intervention, including amplification with a hearing aid, can begin without delay. It is a reasonable goal to have every hard-of-hearing infant identified by two months of age. Any delay in this process deprives the developing brain of the auditory stimulus it requires for normal language development. (Even profoundly deaf newborns can benefit from very early introduction of sign language and may possibly benefit from amplification.) Also, rescreening the infant as an outpatient or proceeding with confirmatory testing requires a baby to be very quiet or asleep. Every month that passes decreases the likelihood that the infant will be in a quiet state at the time of the recheck appointment, and older infants may even require sedation just to perform the testing.

Question: What does rescreening typically involve?

Answer: Rescreening may initially be performed with the same screening techniques used in the hospital, either otoacoustic emission testing (OAE) or automated auditory brainstem response testing (AABR). These screening tests are "physiologic" in the nature of their measurement, rather than "behavioral" testing which requires the observation of a behavioral response in the

*(See **Hearing**, page 31 ▸)*

SICK SCHOOL SYNDROME/
SICK BUILDING SYNDROME (SSS/SBS)

Sick/School/Building Syndrome (SSS/SBS) is an increasingly common problem. Although objective physiological abnormalities are not generally found and permanent sequelae are rare, the symptoms of SBS can be uncomfortable, even disabling, and whole workplaces can be rendered nonfunctional. Similarly schools and school libraries have been closed due to allergic/respiratory problems. Environmental trigger mechanisms are numerous (e.g., cockroaches, rodents, mold and other).

These mixed symptoms are now being commonly recognized. Respiratory symptoms seem to be most frequent. Association with children exposed to mold in water damaged school buildings is frequently documented. Elevated IgE values are found to be more common among the exposed children, as was the occurrence of new allergic disease after the children started school.

In controlled studies in control schools versus problem schools elevated (1,3)-beta glucan exposures were correlated with generally with increased symptoms. Associated with atopy, the extent of symptoms of dry cough, cough with phlegm and hoarseness was similar to the non-atopic in the control school, but significantly higher in the problem schools. This test, by itself or as indicator of molds, is a risk indicator of airways inflammation. Four common problems are identified as contributors. They are moisture, mold, construction materials such as wallboard/ floor and wall coverings, (their adhesives) and inadequate ventilation. So often roof leaks, construction defaults, locker rooms, showers result in continuing water damage/presence. Present day construction tends to limit air flow and thereby the drying process. It has also been shown that many adhesives used in wall and floor coverings act as vegetative media.

In school studies in Lubbock, Texas, five fungal genera were consistently found in the outdoor air and comprised over 95% of the outdoor fungi {Cladosporium (81.5%), Penicillium (5.2%), Chrysosporium (4.9%), Alternaria (2.8%), and Aspergillus (1.1%)}. Studies have identified the association of moisture and mold growth in schools. In 11 schools, the indoor air (complaint areas) fungal ratios were similar to that in the outdoor air.

Eleven schools were cultured for mold where visible growth was seen under carpets, wetted walls, or behind vinyl wall coverings. As a result, it is now determined that Penicillium and Stachybotrys/Black mold species may also be associated with sick building syndrome. In terms of the etiology, studies have shown that moisture is the most common offender in this process, probably the initiating offender.

A specific study sought to determine whether exposure to molds, resulting from moisture damage in a school, was associated with increased respiratory symptoms and morbidity among school children and whether the renovation of this building resulted in resulted in a decrease in prevalence of respiratory symptoms and morbidity. The study followed (1-year interval) children between the ages of 7 and 12 years from two elementary schools . In addition, in a questionnaire completed by the parents, the authors assessed the respiratory health of children by examining the health records of a local health center. In the cross-sectional study, the prevalence of symptoms and infections was higher in the exposed group, as were visits to a physician and use of antibiotics. Therefore, moisture damage and exposure to molds increased the indoor air problems of schools and affected the respiratory health of children.

The problem of dampness in daycare centers and the incidence of employee illness has been studied. Dampness was found in 75.3% of the centers, visible mold in 25.8%, stuffy odor in 50.0%, water damage in 49.3%, and flooding in 57.2%. The prevalence of sick building syndrome symptoms in the daycare workers was statistically significant among those who worked in centers that had mold or dampness. (no data reported for children). Among studies it has been noted that the incidences of dampness or mold in centers were very common in subtropical and coastal regions, and dampness was a strong predictor of sick building.
Ed. Note: Should any reader encounter patients with objective symptoms associated with SKS, I have an investigative protocol from the AAP Safety Net Meeting , March 2001. It is obvious that Florida climate and building construction could be susceptible to the problem. CFW☐

Beware of Pufferfish! FDA warning!

An urgent note for Floridians. Website included for full information. Toxin cannot be destroyed by cooking! -CFW

FDA ISSUES HEALTH ADVISORY ON PUFFER FISH FROM FLORIDA
http://www.fda.gov/bbs/topics/NEWS/2002/NEW00803.html

The Food and Drug Administration (FDA) is warning consumers not to eat puffer fish harvested from the Titusville, Fla., area because these fish may contain a naturally occurring toxin that can cause serious illness or death. Such marine toxins are known to be a byproduct of algae found in seawater.

The symptoms of this toxin are predominately neurological: tingling and burning of the mouth and tongue, numbness, drowsiness, and incoherent speech. These symptoms develop fairly rapidly, within 30 minutes to two hours after eating the fish, depending on the amount of toxin consumed. However, in severe cases, respiratory paralysis and even death may occur. This toxin cannot be destroyed by cooking or freezing. ☐

ad GlaxoSmithKline

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copy of the RB1 gene. As long as each cell contains one copy of the normal gene, retinoblastoma and certain other second non-ocular primary tumors will not develop. However, if a second mutational event alters the only normal copy of the RB1 gene in any single cell, uncontrolled growth may occur. This was hypothesized by Knudson's "two hit hypothesis" well before the development of molecular genetics.[4]

Clinical Presentations of Retinoblastoma

Retinoblastoma is diagnosed at an average age of 18 months with over 90% diagnosed before the age of 5 years. A small number are diagnosed later in childhood, with extraordinary cases first presenting in the teenage years or early adult life. Children with bilateral retinoblastoma are diagnosed at an average age of 13 months, while children with unilateral retinoblastoma are diagnosed at an average age of 24 months. This age discrepancy probably relates to different mutational requirements for malignant transformation in hereditary versus sporadic retinoblastoma.

The most common presenting sign of retinoblastoma is an abnormal appearance of the pupil, which normally should appear black in average room lighting as well as outdoors during daylight hours. The pupillary abnormality can resemble the classic white pupil or leukocoria, described in retinoblastoma, but also observed in a number of other ocular disorders. The appearance of leukocoria has been compared to the reflection of a flashlight from a cat's eye at night. However, as with the reflection from a cat's eye, the abnormal reflex in retinoblastoma is often present only intermittently and only under very specific lighting conditions. In addition, the abnormal reflex may change in character, ranging from white or yellow-white in color to red, orange, or even black, under certain lighting conditions. The only detectable abnormality may be asymmetry, when compared to a normal eye or the child's other eye, if it is normal.

The appearance of the pupillary reflex is influenced by a number of factors, particularly tumor color, size, location and number of tumors, as well as the ambient lighting, direction of the light source, pupil size and the direction the eye is pointed relative to the light source. Other variables also have significant influence on the appearance of the pupillary light reflex, including refractive error, the optical characteristics of the cornea and lens, the status of the anterior chamber, iris, retina and underlying choroid. The quantity and distribution of retinal and choroidal pigment as well as the highly vascularized choroid are particularly important with respect to the intensity and color of the red reflex seen in the direct ophthalmoscope as well as the "red eye" seen with some flash cameras.

The examiner's view of the child's eyes with the direct ophthalmoscope is also influenced by the same factors, which creates a number of potential diagnostic pitfalls in the primary care setting. Lighting in most commercial buildings, including most of our offices, is bright, diffuse, and originates from directly overhead. In addition, the light from our examining equipment, whether it is a flashlight or a direct ophthalmoscope, originates from nearly the same position as the examiner's eyes. These sources of lighting differ from the lighting in our homes, which usually is provided by lamps. Lamps are typically less bright, less diffuse, and displaced to the side as well as slightly above, the child. This provides unique illumination of the pupils, which is not duplicated in our examining rooms. This means that parents have had the opportunity to view their child's eyes under conditions that are not duplicated in our offices. Occasionally, the parents will observe a problem that cannot easily be seen with equipment used in the primary care setting.

Photographs can also be used to identify abnormal pupillary light reflexes. At times, parents will identify the abnormal reflex in home photographs and bring the pictures to the pediatrician. It is imperative for the pediatrician to carefully evaluate the history, examine the child, and review the photographs that are perceived by the parents to show an ocular abnormality. In many instances, it may be appropriate to refer the child for a comprehensive ophthalmologic evaluation, which should include dilation, and review of the same photographs. On occasion, photographs have been used to establish that an earlier examination failed to detect a tumor or other lesion that was identified on a later examination. Many cameras now have a "pre-flash", which constricts the pupils before the final flash occurs, at which time the actual photograph is taken. This effectively eliminates the red reflex, a potentially important clue to the presence of certain ocular disorders, including retinoblastoma.

The second most common presenting sign of retinoblastoma is strabismus, which occurs in approximately 20% of children with this tumor. The misalignment may be expressed as an esodeviation, exodeviation or vertical deviation. The strabismus can be constant or intermittent and may not be present on the day that the child is examined. Because of the association between strabismus and retinoblastoma as well as the association of strabismus with other ocular, neurologic, and systemic disorders, every child who develops strabismus should be referred in a timely manner for a comprehensive ophthalmologic examination, including dilation.

Unfortunately, the combination of intermittency and variable appearance of abnormal pupillary reflexes as well as strabismus creates significant problems with respect to the family's ability to detect and describe the abnormality. To make matters more difficult, parents generally do not understand ophthalmic anatomy, optics, or visual physiology and, as a consequence, often have difficulty expressing what they have observed. However, parents typically look closely at their children's eyes and have the opportunity to make their observations over prolonged periods of time and under different lighting conditions. Rather than describe the actual appearance of an abnormal pupillary reflex or intermittent strabismus, many parents will report that their child's eyes show a "glazed look" at times, are "lazy" or simply state "my child's eyes don't look right". These important characteristics may be underemphasized in the primary care pediatric literature.

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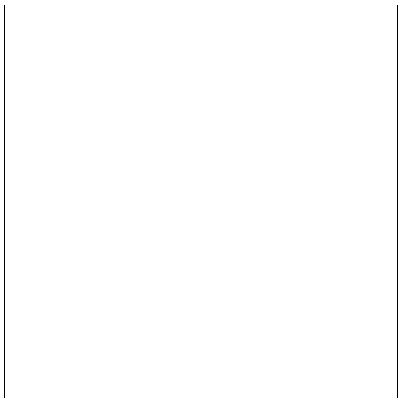
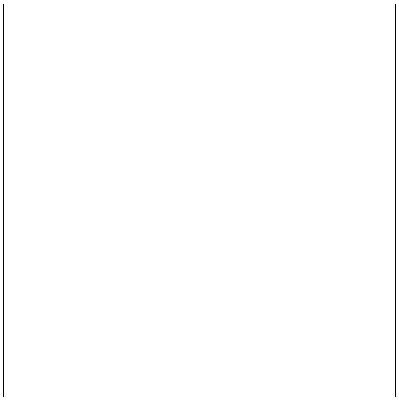


Figure 1

Figure 2



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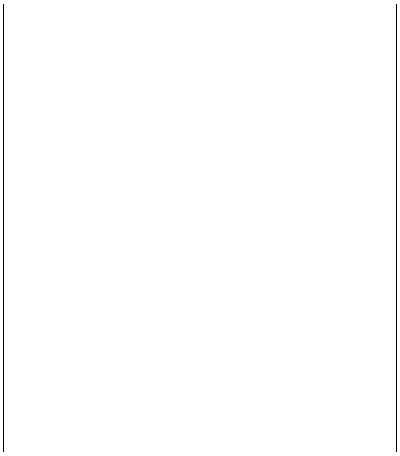

Figure 5

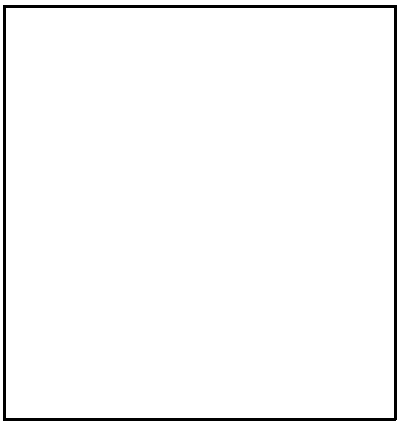

Figure 6

Legends:

Figure 1: 3-year old whose parents report: “My child’s eyes don’t look right

Figure 2: View of normal appearing left pupil of the 3 year old girl shown in Figure 1. The photo is taken under standard room lighting in the doctor’s office. The red reflex and fundus appear normal when the direct ophthalmoscope is used.

Figure 3: View of same ppil as shown in Figure 2 in slightly darkened room and from slightly different angle. The retinoblastoma is easily seen under these conditions, growing inwards from the nasal side.

Figure 4: CT scan showing intraocular calcified mass representing retinoblastoma

Figure 5: One of a sequence of monthly photographs taken by the family of this 8 month old infant. There is a subtle difference in the pupillary reflex between the right and left eye. The reflex in the right eye is black, while the reflex on the left is red. There is a retinoblastoma on the right. This photograph documents the time of onset of the retinoblastoma. Earlier photographs showed normal symmetrical red reflexes.

Figure 6: Home photograph showing asymmetric pupillary reflexes in a girl wilth the CHARGE association. There is a retinal and choroidal coloboma in the right eye, which creates a white pupillary reflex. Both the right and left eye have iris colobomas which create “keyhole” shaped pupils, partially hidden by the lower lids.

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Atypical Presentations of Retinoblastoma

Most children with retinoblastoma will present with leukocoria, other pupillary light reflex abnormalities, or strabismus. Retinoblastoma can also present in other ways, at times mimicking other disorders. Diagnostic confusion and delay in diagnosis are more likely when retinoblastoma masquerades as glaucoma, orbital cellulitis, uveitis, heterochromia iridis, hyphema, or intraocular bleeding posterior to the lens (retinal or vitreous bleeding).

Atypical presenting signs of retinoblastoma include evidence of poor vision in one or both eyes, an irritated red eye or eyes, excessive tearing, buphthalmos (enlargement of the eye) and corneal clouding from elevated intraocular pressure. Heterochromia of the iris can occur for several reasons, including iris neovascularization, tumor cells in the anterior chamber or on the iris, and small amounts of blood in the anterior chamber. Obvious blood in the anterior chamber occurs in the form of a spontaneous hyphema or a hyphema after very mild trauma. Unlike hyphema, bleeding in the posterior aspect of the eye, including retinal as well as vitreous bleeding, usually is not detectable on casual observation in ambient light, but can cause a loss of the red reflex under conditions when the red reflex should normally be present. If the other eye is normal, this may appear as a black pupil when the opposite eye shows a red reflex.

Case Presentation (See Figures 1 - 6)

Shortly after completing my training, one of my early patients was a beautiful little girl whose mother reported that her daughter's eyes "did not look right". She was evaluated by several excellent pediatricians in the Boston area. Each examiner found the child's eyes to be normal. This included her ability to visually fixate on a small toy and track the toy as it was moved into different gaze positions, with each eye tested separately. In addition, the direct ophthalmoscope showed a normal red reflex in each eye, as well as a normal appearing optic nerve and macula in each eye. Because of nothing more than the history provided by the mother, the child was referred for a comprehensive ophthalmologic examination. She was found to have a unilateral retinoblastoma, which was growing inwards from the peripheral retina. When the pupils were relatively small in ambient room light as well as in a slightly darkened room, the red reflex appeared normal, as did the posterior retinal structures using a direct ophthalmoscope. However, when the room lights were darkened and the examiner modified the technique slightly, the retinoblastoma could be detected. The examiner's face was placed about 3 feet away from the child in a semi dark room. The direct ophthalmoscope was set on plus 1 (black or green #1 on most ophthalmoscopes) and the large circle of light was selected. The lower edge of the circle of light from the ophthalmoscope was initially placed on the child's forehead, just above the eyebrows. The examiner's eye was focused on the child's forehead. The light was then brought downwards to illuminate both eyes simultaneously, while the examiner observed the child's pupillary light reflexes, before the pupils constricted from the light of the ophthalmoscope. In this manner, the examiner was able to observe the light reflexes at a time when the pupils were reasonably large. The retinoblastoma could be observed growing in from one side, hidden by the iris when the pupil was smaller in diameter.

Differential Diagnosis

Retinoblastoma must be distinguished from other disorders, some of which are also quite rare and generally known only to ophthalmologists. The list of conditions which must be distinguished from retinoblastoma includes: cataract, persistent fetal vasculature (persistent hyperplastic primary vitreous or PHPV), cicatricial retinopathy of prematurity, retinal detachment, intraocular inflammation from toxocara canis (larval granulomatosis), exudative vascular disorders such as Coat's disease, retinal dysplasia, retinal hamartomas, as well as other disorders. Most of the time, these disorders can be distinguished from retinoblastoma by their appearance as well as characteristics on supplemental studies. However, on occasion, retinoblastoma cannot be completely eliminated from consideration by examination findings and special studies. This is most likely to occur with advanced disease that has significantly disrupted the normal architecture of the eye and already blinded the eye. Disorders that can occasionally be difficult to distinguish from retinoblastoma include: advanced Coat's disease, severe PHPV, and intraocular granulomatous inflammation caused by toxocara canis.

Examination by the Ophthalmologist

Children suspected of having a retinoblastoma as well as children with other potential serious ocular disorders must receive a prompt comprehensive ophthalmologic examination, which includes a dilated fundus examination. The pediatrician should be aware that ophthalmology patients tend to fall into two widely separated age groups: the very young and the very old. It is important to select an ophthalmologist who is experienced and comfortable with pediatric eye examinations and familiar with the variable clinical presentations of retinoblastoma.

The eye examination should include evaluation of the child's visual acuity using age appropriate techniques, ocular alignment and eye movements, the pupils, slit lamp examination of the anterior segment of the eye, and a dilated fundus examination with indirect ophthalmoscopy, as well as objective measurement of the child's refractive error. On rare occasions, ophthalmologists who have neglected to perform a dilated examination have failed to detect retinoblastomas.

Special studies are often employed in the initial examination, including ultrasonography, fundus photographs, as well as CT scans, MRI, and other studies. Retinoblastoma has a propensity to form calcifications within the tumor, which can usually be identified on CT scan and ultrasound. Intraocular calcification can be very helpful when attempting to distinguish a retinoblastoma from other lesions.

Examination under anesthesia is often an essential component of the evaluation and can be of great importance in confirming the diagnosis and clinically staging the tumor by

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identifying the size, location and number of lesions. If indicated, a bone marrow aspiration, spinal tap and other studies may be performed under anesthesia.

Tumor Growth Within the Eye

Each retinoblastoma presumably starts with a single cell that repeatedly divides. There is a threshold, below which the tumor is too small to be seen. Using special examining equipment, such as the indirect ophthalmoscope, the ophthalmologist has the opportunity to observe tumors as they first become visible, particularly when serial examinations under anesthesia are performed on children with hereditary retinoblastoma. These tiny tumors appear as subtle translucent gray to gray-white areas of thickened retina, measuring several hundred microns across (retinal veins are approximately 100 microns in diameter at the edge of the optic nerve). When the pediatrician uses the direct ophthalmoscope, its limited field of view makes detection of a retinoblastoma at this very early stage highly unlikely, even with dilation of the pupil.

With small tumors, the visual acuity is likely to be normal, unless the tumor reduces the quality of visual information sent to the brain from the center of the macula. If this occurs, visual fixation and following abilities may be subnormal in the affected eye when the opposite eye is covered and strabismus may occur, often intermittent at first.

As the tumor grows, blood vessels can usually be observed on the surface as well as in the tumor itself and the tumor generally becomes less translucent and more opaque. Eventually the tumor becomes large enough to alter the red reflex, but this depends on several factors, including tumor size, tumor location, pupil size, and direction of gaze.

Retinoblastoma shows several growth patterns within the eye, which can also affect the clinical presentation in the primary care setting as well as the ophthalmologist's office. Tumor growth that is directed towards the center of the eye and into the vitreous cavity is referred to as endophytic growth. Tumor growth that is directed away from the center of the eye, deep to the retina, is referred to as exophytic growth. Exophytic growth is more likely to cause retinal detachment, choroidal invasion, and optic nerve invasion. It is also more likely to be associated with disseminated disease and tends to be more difficult to detect on clinical examination, since retina covers the tumor. Both endophytic and exophytic growth are associated with calcification, which is usually best demonstrated on CT scan and ultrasonography. A third growth pattern is diffuse infiltrating growth, in which no mass forms. These tumors rarely develop calcification and diffuse growth can be very difficult to diagnose, even for the experienced ophthalmologist using special equipment.

Tumor Spread Beyond the Eye

Retinoblastoma has a predilection to invade the optic nerve where it can travel posteriorly within the nerve to the brain or via the nerve sheath into the CSF in the subarachnoid space and then to the brain and spinal cord.

Hematogenous spread of retinoblastoma also occurs, resulting in distant metastases, primarily to the bone marrow, bone, lymph nodes, and liver. When the tumor is very small and confined to the retina, the blood supply is usually provided by the retinal blood vessels. As the tumor grows, these retinal blood vessels may become dilated and tortuous, often referred to as "feeder vessels". With further growth, the tumor can extend through the deeper retinal layers, including the retinal pigment epithelium and Bruch's membrane to invade the highly vascularized choroid, which is located just beneath the retina. The choroid is the second but perhaps most important, intraocular route for hematogenous spread.

Metastatic spread of retinoblastoma tends to occur early and is uncommon beyond 3 years following treatment. Children who do not receive treatment typically die of their disease within 2-4 years of the onset of symptoms or signs.

Second Malignant Neoplasms in Survivors of Hereditary Retinoblastoma

Survivors of hereditary retinoblastoma have a significant risk of developing second non-ocular malignant neoplasms later in life. [5,6]

In the early 1980's several children with bilateral retinoblastoma (always hereditary) developed midline intracranial neoplasms in the suprasellar or pineal area (pineoblastoma).[7] There was compelling evidence that these lesions represented new primary tumors, rather than direct extension or metastasis from the primary intraocular tumor(s). "Trilateral retinoblastoma" refers to the association of retinoblastoma (usually bilateral) and a primary midline intracranial neoplasm. The name was developed because the pineal gland has been referred to as the "third eye" and pineal cells share a number of histologic features with retinal photoreceptors. In a meta-analysis of 106 children with trilateral retinoblastoma, the median age at diagnosis of the retinoblastoma was 5 months (range 0 to 29 months) and the median time from diagnosis of the retinoblastoma to the diagnosis of the intracranial lesion (trilateral retinoblastoma) was 21 months. A few children developed their intracranial tumors before their retinoblastoma (range 6 months before to 141 months after diagnosis of the ocular tumor).[8] Most of the children with trilateral retinoblastoma probably would have survived their ocular tumors, however, the new primary intracranial neoplasms were fast growing and aggressive, resulting in a very high mortality rate. Although frequent screening by neuroimaging has resulted in survival in a few cases, the mortality rate remains high for trilateral retinoblastoma.

Later in childhood and adult life, sarcomas represent the most frequent non-ocular second malignant neoplasm in survivors of hereditary retinoblastoma. Osteogenic sarcoma is the most common. The risk of acquiring this tumor is increased approximately 500-fold over normal in survivors of hereditary retinoblastoma. External beam radiation therapy in these children appears to substantially increase the likelihood that such tumors will occur in the field of treatment later in life. Sarcomas also commonly develop at sites far removed from areas that may have

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Scientific

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received radiation therapy for the primary eye tumor. Other malignant tumors encountered in patients with a history of hereditary retinoblastoma include fibrosarcoma, malignant fibrous histiocytoma, leiomyosarcoma, and others.[9,10,11]

Treatment of Retinoblastoma

If the examining ophthalmologist is not an expert in the management of retinoblastoma, strong consideration should be given to referring the child immediately to an ophthalmologist experienced in the treatment of this rare tumor. Such individuals are usually located in large referral centers, with a team of experts consisting of pediatric oncologists, imaging centers, radiation therapists, and others. This is particularly important, since there now are many forms of treatment and various modalities may need to be employed sequentially. The choice of treatment has significant impact on the child's survival as well as the survival and visual capabilities of the affected eye or eyes. The risk of later development of a second non-ocular neoplasm may also be significantly influenced by the treatment modalities utilized for the primary retinoblastoma, particularly when external beam radiation therapy or certain forms of chemotherapy are used to treat hereditary retinoblastoma.

Treatment options for retinoblastoma include: chemotherapy, chemoreduction combined with other forms of therapy, enucleation, external beam radiation therapy, episcleral plaque radiation therapy, cryotherapy, photocoagulation, laser therapy, photodynamic therapy, and others. The specific choice of treatment modality depends upon the hereditary or non-hereditary character of the tumor, the size, location, and number of tumors, the status of the opposite eye, as well as other factors. A discussion of the rationale for choosing a specific form of treatment goes well beyond the scope of this article.

Conclusions

Retinoblastoma is a very rare but important intraocular tumor that presents a number of diagnostic pitfalls in the primary care setting. A number of these pertain to variations in the clinical findings over time and under different conditions, a propensity for the tumor to masquerade as other disorders or as a normal examination, the requirement for special ophthalmic diagnostic techniques to detect a some tumors, and the hereditary features of retinoblastoma. The critical relationship of tumor stage to survival of the child as well as visual outcome makes early diagnosis of paramount importance.

Websites of Interest

1) National Center for Retinoblastoma www.ncbi.nlm.gov/disease/Retinoblast
2) Online Mendelian Inheritance in Man www.ncbi.nlm.nih.gov/disease/Retinoblast
3) The National Retinoblastoma Research and Support Foundation www.djo.Harvard.edu/meei/PI/RB/NRRSF.html
4) Retinoblastoma International www.retinoblastoma.net
5) For additional sites: Search under Retinoblastoma www.google.com

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6) Eng C, Lin FP, Abramson DH, et al. Mortality from second tumors among long term survivors of retinoblastoma. *J Nat Cancer Inst.* 1993; 85: 1121-8.
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10) Smith LM, Donaldson SS. Incidence and management of secondary malignancies in patients with retinoblastoma and Ewing's sarcoma. *Oncology*. 1991; 5: 135-41.
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President

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As you know the American Academy of Pediatrics Committee on State Governmental Affairs selected Senator Debbie Wasserman-Schultz as the 2001 Legislator of the Year. I am now delighted to announce that Congressman Bill Young (R-St. Petersburg) has been selected by the American Academy of Pediatrics Committee on Federal Governmental Affairs as the Outstanding Federal Legislator for 2001. We are hoping to present his award to him during the Annual meeting in Orlando. Congressman Young has a long history of being a very strong advocate for children and has been key in the development of the EMS for Children Program and the Poison Control Network. We are very proud of these two outstanding legislators and deeply appreciate what they have done for children and pediatricians throughout their careers.

Even though the challenges were great and the victories were small I am encouraged by the energy and dedication of our Executive Committee and our membership. Without a doubt we can and will do more for pediatricians and children in the state of Florida in the months ahead. As always I appreciate the opportunity to serve as your President. With warmest regards,

Richard L. Bucciarelli, M.D.
President, FCAAP□

Editorial

(continued from page 5)

accuracy, by looking for the red reflex and questioning the reflex that does not look perfect. This is a procedure we all do, and well.

We have really had enough insults to our dignity as professionals. Need we accept more? Or should we, as dignified professionals, raise our voices, singly and collectively, in total objection to this type of legislation? If we do not, we will open ourselves to more and more incursions into our lives and our cherished discipline.

Have a good Spring season.

Herb Pomerance
Editor□

"Crippled"

(◂ continued from page 11)

Consequently, issues of continuing health care and employment for these young people are quite new. Indeed, the first generation to fully benefit from life-prolonging advances is now coming of age. In the past only pediatric practitioners were trained to manage these diseases of childhood. Most adult practitioners are not capable, by education or experience, of managing the care of this new cohort of adults with children's special health care needs. The image of a 30-year-old patient sitting in a pediatric waiting room seems inappropriate. Are adult hospitals properly equipped to care for adults with these rare childhood illnesses or should children's hospitals prepare to purchase larger beds and other equipment?

Employers have recently begun to understand the accommodations necessary to hire adults with physical and mental challenges. They have not yet begun to experience the impact of these adults with children's special health care needs. How will this new group of young adults impact the employers' fringe benefit plans, including provision of health insurance and sick leave?

In addition to these concerns with the systems of health insurance, health care delivery and employment, there is the concern of the aging parents of the older children with special health care needs. As principal financiers (through their own insurance), many of these parents are concerned with how their children will finance their own health care once they are too old to be included on the parents' policy. Will their child have to become eligible for public assistance in order to find insurance? Will parents continue to be responsible for future health care costs?

All of these questions and more are challenges to parents, health care professionals, administrators and policy makers. Some of the challenges can be met by:

- A greater understanding of these transition issues from the perspective of youth and young adults with special health care needs and their families.
- Improving current health care transition practices in public and private health care systems by developing coordinated and continuous systems of care that are adequately financed.
- Educating youth about health insurance, improving health insurance and other financing options for youth with special health care needs; while promoting improved health benefits packages.
- Enhancing knowledge and skills related to how the personal preferences and interpersonal behavior of youth, families and professionals will impede or promote health care transition.
- Requiring the development of transition plans; including skills in developing such plans, plus promoting use of such plans in public and private pediatric and adult health care systems.

Summary

Currently, a fairly large "first generation" of young people with a chronic health condition or medical disability is coming to adulthood. This number will steadily increase. Over 90% of children born today with a chronic or disabling health condition are expected to live more than 20 years. Using a children with special health care needs prevalence rate of about 15%, it is estimated that more than 500,000 such children in the United States will turn 18 every year. The need to plan for and accommodate the special ongoing needs of this group of young adults and their families is becoming acutely apparent. Parents, practitioners and policy makers are challenged to make Florida a leader in proving creative and humane responses to this special generation of young people.☐

Chairmen

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provide a single research award each year, competitively selected, for the most outstanding research in the building. In addition to the funds for the research laboratory, the gift specifies that 25% of the annual minimum award of $300,000 (which amounts to $75,000) will go to the investigator as a personal award. Its purpose is to inspire excellent work in the building, and it is very likely that it will be successful!

In recent days, the Department has been notified of the award of major private grant from the Anne E. Dyson Foundation Community Pediatrics Training Initiative. This multi-year grant, under the Direction of Drs. Charles Pegelow and Arturo Brito will provide long term support to educate pediatric residents about social, legal, political and economic factors that affect child health, provide pediatric residents with the opportunity to collaborate with Community Based Organizations experienced in child advocacy, will solidify the departmental infrastructure for community advocacy by implementing a self-sustaining model for collaboration among faculty, residents and CBOs, will strengthen child advocacy by increasing interdisciplinary efforts, and will provide model training in cultural competency to prepare the next generation of pediatricians as community advocates. The faculty, and Housestaff (who were very involved in prepared the grant application and in the site-visits) are very excited about the extraordinary opportunity that this major grant will provide.☐

Region II

(◂ continued from page 6)

CHORES (A Children's Hospital Organization for Relief and Educational Services) continues its volunteer outreach efforts, headed by Dr. Doug Campbell, with region members who participated in outreach efforts in Grenada, Malaysia and the Philippines. Recently a number of fundraisers were held and were quite successful. Resources are being used to provide extensive orthopedic care to a child from Grenada.

The new Ronald McDonald House has recently opened. The Florida Pediatric Society continues to be a strong supporter of this tremendous asset for the region's children. Indeed our most recent meeting was held at the conference room at the Ronald McDonald House and included a tour of the facilities. This was very well received.

Current plans are underway to enhance our membership. With the assistance of Edie Lovingood, contacts are made with the pediatricians who are new to the area and we have been very successful at convincing them of the value of the organization. However, we continue to lose many of the more experienced pediatricians who opt out of membership. Plans are underway under the direction of Dr. Jim Waler to try to convince these former members of the value of the work of the organization.

Dr. Jay Whitworth and Dr. Tom Chiu in conjunction with the Shands Teaching Hospital and Dr. George Armstrong through Wolfson Children's Hospital are spearheading efforts to improve educational opportunities for both the resident staff and the pediatricians through the use of teleconferencing techniques. This allows interaction at the Grand Rounds Program at the Shands Teaching Hospital as well as Wolfson Children's Hospital and has lead to very spirited and informative case discussions.

Plans are currently underway for a society social event in the fall. In the meantime we look forward to seeing our colleagues at the annual meeting of the Florida Pediatric Society in Orlando.

Respectfully submitted

Donald George, MD
Regional Representative☐

(◂continued from page 22)
infant.

Question: What should parents be told if their newborn does not pass the screening test in the hospital?

Answer: First, parents should be reassured. Most infants who do not pass the hospital-based test are eventually shown to have normal hearing. But parents should not be complacent – every baby who fails the initial screen must return for follow-up. If the child is subsequently identified as having a congenital hearing loss, parents should know that early intervention has been shown to have dramatic results, with subsequent language development at near-normal levels. Parents will never need to say, "If only I had known sooner."

Question: What about the infant who only fails the screening in one ear?

Answer: Even though unilateral hearing loss may be a less severe condition than bilateral hearing loss, these infants also deserve prompt follow-up. If a unilateral hearing loss is confirmed, the parents can be counseled about how to maximize the child's language development by being sure that the auditory stimuli are reaching the better ear effectively. But equally important, some of these children have progression of hearing loss in the ear that initially passed screening. In addition to re-screening, any child with a confirmed unilateral hearing loss must be followed closely over time to assure that the condition does not evolve into a bilateral hearing loss.

Question: What can parents expect in an audiologic evaluation if the infant does not pass the rescreen?

Answer: Most importantly, the primary care physician should make sure that all follow-up and confirmatory testing is performed by pediatric audiologists with experience testing infants and fitting them with hearing aids, even if this requires extra travel for the infant and the family. You can determine who is a qualified pediatric audiologist by asking how many infants that provider has seen in that month, and whether he or she has expertise in using physiologic and behavioral methods to test hearing in infants. Neurologists also use Auditory Brainstem Responses to evaluate the integrity of the brainstem in specific neurological disorders. This assessment is inherently different from the pediatric audiologist's assessment using ABR to evaluate infant hearing; thus referral to a neurologist for an infant hearing assessment is not recommended.

Explain to parents that they can expect the audiologist to administer a battery of tests to assess the integrity of the auditory system from the outer ear through the inner ear and even the brain stem. This confirmatory testing is also performed using "physiologic" testing, typically including a standard diagnostic Auditory Brainstem Response (ABR, also known as BAER) along with additional OAE testing. The ABR may include different types of stimuli and assess the system for air conduction and bone conduction. Testing for middle ear function will also be done. The test battery may require several visits to accurately characterize the hearing loss.

Behavioral testing techniques are reliable after an infant is 6 to 12 months old – far too late to allow for early intervention and amplification, but they should become a part of the test battery used in the ongoing assessment on the infant with hearing loss.

Question: If a child is confirmed to have congenital hearing loss, what else should the primary care physician do?

Answer: Address family concerns. Families will need help understanding this new medical development. Work closely with the audiologist to better understand the nature and degree of the hearing loss. Pediatricians should interface with professionals in education to provide families with needed services for the infant with hearing loss.

Arrange for a complete evaluation by an otolaryngologist or otologist with experience working with infants and young children. Some children require further evaluation to assess the potential of progressive hearing loss, and all require the specialist to give medical clearance for the use of a hearing aid.

As we discover the increasing frequency of genetic syndromes among children with congenital hearing loss, it is recommended that these families also be referred to a medical geneticist with experience in the field of congenital hearing loss. Thirty percent of hearing loss is of uncertain etiology and there are more than 200 syndromic and non-syndromic forms of hearing loss that have been identified; about 20 percent will have associated clinical findings.

Every affected newborn should have a complete evaluation by a pediatric ophthalmologist, to assure that the visual stimuli to the brain are in no way compromised, and to assess for any associated eye anomalies or genetic syndromes with both visual and auditory impairment.

After hearing loss is confirmed, physicians need to be involved in the following:

- Coordinating services with the Individuals with Disabilities Education Act Part C agencies. Part C agencies are responsible for Child Find and intervention for children with disabilities.
- Monitoring middle ear status to avoid further compromise to hearing.
- Monitoring developmental milestones because 30-40 percent of children with hearing loss will demonstrate multiple disabilities or delays.

Question: What does audiologic habilitation mean? What does it entail?

Answer: Audiologic habilitation includes hearing aid fitting. Hearing aid fitting proceeds when audiologic, otolaryngologic and other medical evaluations are in accord and the parent is in agreement with this recommendation. The fitting should take place in the first months of life; this is possible based on physiologic testing alone to provide maximum access to the acoustic features of speech in a safe listening range.

As physicians, we have all learned to respond quickly to an abnormal newborn screening test for PKU or hypothyroidism. It is time now for us to respond with similar urgency when a newborn does not pass the initial hearing screening test. Please contact me if you have any questions regarding the information contained within this article. I can be reached at Tallahassee Memorial Hospital, (850) 431-5354 or 431-2295.

Visit the following Web sites for more information:

National Center on Hearing Assessment and Management www.infanthearing.org.

Boystown National Research Hospital, Center for Hearing Loss in Children www.babyhearing.org□

AAP NATIONAL CONFERENCE AND EXHIBITION

(Formerly AAP Annual Meeting)

2002	Boston, MA	October 19-23
2003	New Orleans, LA	November 1-5□

Upcoming Continuing Medical Education Events

THE FLORIDA PEDIATRICIAN will publish Upcoming Continuing Medical Education Events planned. Please send notices to the Editor as early as possible, in order to accommodate press times in February, May, August, and November.

Program: Practical Pediatrics
Dates: May 16 - 18, 2002
Place: Eldorado Hotel and Sweeney Convention Center, Santa Fe, N M
Credit: Up to 16.5 hours for Category 1 for AMA Physician Recognition Award
Sponsor: American Academy of Pediatrics
Inquiries: American Academy of Pediatrics, (800)433-9016, ext 6796 or 7657

Program: 33rd Annual Pediatrics Symposium: Keeping Children Shipshape
Dates: May 25-27, 2002
Place: Sandestin Beach Hilton Golf and Tennis Resort
Credit: Up to 14 hours for Category 1 for AMA Physician Recognition Award
Sponsor: MECOP and Sacred Heart Children's Hospital, Pensacola
Inquiries: MECOP, (850)416-6557 or www.mecop.org

Program: Practical Pediatrics
Dates: May 23 - 25, 2002
Place: Hilton Head Marriott Beach and Golf Club, Hilton Head Island, SC
Credit: Hour for hour for Category 1 for AMA Physician Recognition Award
Sponsor: American Academy of Pediatrics
Inquiries: American Academy of Pediatrics, (800)433-9016, ext 6796 or 7657

Dates: June 21-23, 2002
Place: Amelia Island Plantation, Amelia Island, FL
Credit: Up to 13 hours for Category 1 for AMA Physician Recognition Award
Sponsor: Nemours Foundation, Jacksonville, FL
Inquiries: Jacquelyn A. Nolan, Director CME (904)390-3638 or (800)767-5437 ext. 3638

Program: Practical Pediatrics
Dates: June 28 - 30, 2002
Place: J.W.Marriott Hotel, Washington, DC
Credit: Up to 16.5 hours for Category 1 for AMA Physician Recognition Award
Sponsor: American Academy of Pediatrics
Inquiries: American Academy of Pediatrics, (800)433-9016, ext 6796 or 7657

Program: Practical Pediatrics
Dates: August 30 - September 1, 3003
Place: Québec City, Québec, Canada
Credit: Hour for hour for Category 1 for AMA Physician Recognition Award
Sponsor: American Academy of Pediatrics and Canadian Paediatric Society
Inquiries: American Academy of Pediatrics, (800)433-9016, ext 6796 or 7657

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