President’s Message

Anne Edwards, MD, FAAP

Spring may come late to Minnesota, but once it arrives, a sense of energy abounds. As president of the MN-AAP, I sense the enthusiasm of pediatricians throughout the state working together as providers, with families to further the well being of children in the state. It is through these partnerships that the MN-AAP strengthens its efforts.

Our Medical Home initiative for children with special health care needs has been implemented in 22 clinics throughout the state in partnership with the Minnesota Department of Health and the Minnesota Department of Human Services. The national AAP recognized this program with a special achievement award in 2007, including special recognition of Jeff Schiff, past-president, for his efforts surrounding this project.

Additionally, MN-AAP received national funding to implement the Minnesota Child Health Improvement Partnership: a public/private partnership to assure optimal child healthcare by creating and supporting continuous quality improvement in clinical practices. Through collaborative efforts between MN-AAP, MDH and DHS, this improvement partnership began its initial quality improvement project to support improved mental health and developmental screening in 11 clinics.

MN-AAP continues to advocate for the children of the state through legislative agenda items based on feedback from members during 2007 based on the strong leadership of our policy chair, Megan Jennings and our lobbyist, Sara Noznesky. Agenda items include efforts to increase access to quality health care for all children, to improve required standards for child restraints and to address child obesity. By serving as the fiscal agent for Reach Out and Read, the MN-AAP supported this program involving over 48 participating clinics statewide that annual reaches over 37,000 Minnesota children.

Looking to the future, a priority is to continue to develop the chapter as a common place for all pediatricians in the state to connect in addition to being the source of information and education. Members report they are looking to the MN-AAP for ways to connect on common issues through our website, committees, CME and social meetings. Developing these forums for connection is a goal. In the coming months, the MN-AAP will launch its new website to provide improved communication and connections with members. Thank you to board member, Gordy Harvieux for all his work on this effort.

Finally, spring is never without change, bringing new energy. In February, Katherine Cairns joined the MN-AAP as our new executive director. She brings a wealth of experience in public health and advocacy to the position, and most importantly a passion for children and the efforts of MN-AAP. I want to extend a personal invitation to each of you to attend our annual meeting to have the opportunity to welcome Kathi. I look forward to connecting with you at the meeting. Please continue to contact me with suggestions for the MN-AAP at aredwards@aap.net
Greetings Friends and Colleagues,

I am writing this newsletter on a classic Minnesota morning with a bright cloudless sky. We have had our share of below zero temperatures this past winter, but can hardly complain being cognizant of Madison’s 80+ inches of snow, Illinois’ repetitive storms, and Iowa’s ice and rain. We all have our own stories of winter in this District.

We just completed our five-day marathon AAP Board meeting and although the days are long and different from our usual routine there is so much exciting work the time speeds by.

Renee Jenkins hit the ground with both feet running as our new President. She is an optimistic realist and is going to get a lot done since she is very efficient. We got to see her work with AAP Staff first hand facing down ABC over the ‘Eli Stone’ program that confused the issue of vaccines and autism. ABC wouldn’t halt the programming but we got great national press defining the immunization autism issue.

Jay Berkelhamer continues an active role in Academy leadership as the immediate Past President. Now that his plate is full instead of overflowing it was apparent he made the time to engage District Chairs individually and listen to their issues. Jay has lots to say but what impressed me most over the past year was his capacity to actively listen, conclude and summarize. He introduced most of us to America’s Promise Alliance and remains active in promoting this cause. Please take a minute and go to their website and familiarize yourself with all the good work this group is doing for kids.

Speaking of leadership, Errol Alden our Executive Director is doing a fantastic job; he has the respect of the entire AAP Staff and leads by example. Everyone who works for him understands the mission and principles of the Academy and they are acknowledged for their hard work and success. The staff takes obvious pride in what they do for pediatricians and the world’s children.

Continuing the review of our fulltime Pediatric Staff, the Associate Executives include Bob Perelman, Fan Tait and Roger Suchyta. Bob leads the staff on all things educational at the Academy, Fan among other things leads the Medical Home projects and Roger Suchyta is ever present stewarding policy statements, technical reports and clinical reports from concept to publication.

The Academy is hard at work on new initiatives in Quality Improvement, Clinical Information Technology, Resident Education, Practice Management, Research and Surveys and Child Advocacy. Jackie Noyes and her staff in Washington work tirelessly to assure children’s issues are heard from SCHIP, MediKids, Child Safety to Vaccine Funding.

Speaking of Chapter success- if you are looking for help on a project you probably don’t have to go much farther than a neighboring Chapter for advice. Kansas has successful programs on Obesity, Reading and Oral Health. Illinois is a national leader in office based education. Minnesota has a successful Medical Home Project. North Dakota has the answer to Chapter communication. This just acknowledges a few hot topics, every Chapter in the District has something innovative going on. Check with your leadership and Executive Director for solutions to your problem or challenges.

My next newsletter will explore specific projects at the National level that are being developed to meet your needs and those of your patients.

One final note please make a habit of frequent visits to www.aap.org it is continually improving and has a wealth of information just a click away.

Until next time, make every day a testament to why you chose Pediatrics- the most fulfilling specialty in medicine.
ANNUAL MEETING
The Minnesota Chapter, American Academy of Pediatrics
The Minnesota Academy of Pediatrics Foundation

Friday, June 13, 2008
The Depot- Minneapolis   225 Third Ave. South   Minneapolis, MN 55401

6:00 – 7:00 P.M. – Reception and Networking
7:00 P.M. – Dinner, Guest Speaker, District and Chapter Reports and Awards

Distinguished Service Award presented to:
Amos Deinard, MD, MPH

Child Advocacy Award presented to:
Minneapolis Crisis Nursery

Registration for MNAAP Annual Meeting or Educational Session
To register, send/fax form and payment by June 9, 2008

Name: ______________________________________________________________
Address: ____________________________________________________________
Phone: __________________________ E-mail: _____________________________

☐ $50 per member (or guest) for Annual Meeting Dinner
☐ $10 per resident (or guest) for Annual Meeting Dinner
☐ $45 per MN AAP member for Educational session
☐ $55 for non MNAAP members for Educational session
☐ $35 for practice management team members from MN AAP member clinics
☐ No charge for medical resident for Educational session

Payment Method:
Check in the amount of $______ made payable to: MN Chapter- American Academy of Pediatrics or a Purchase order must accompany this form.

☐ I am paying $_____ on my ☐ Visa  ☐ Mastercard

Card Number________________________  Expiration date_______  Signature__________________

Questions: cairns@mnaap.org or call 651-402-2056. Reservations for hotel rooms, including 4 free water park passes, can be made by calling The Depot directly at 612-375-1700.

Pediatric Developmental and Behavioral Health Screening and Reimbursement
Saturday June 14, 2008   8am -Noon   The Depot, Minneapolis

Speakers include:
Betsy Murray, MD, MPH, FAAP Assistant Professor, Developmental/Behavioral Pediatrics, University of Minnesota
Dave Tilstra, MD, FAAP, CentraCare Pediatrics
Glenace Edwall, PSyD, PhD, LP Director of the Children’s Mental Health Division at the Minnesota Department of Human Services (DHS)
Susan Castellano Manager of Maternal and Child Health Assurance with the Minnesota Department of Human Services
Meredith Martinez, MPH Maternal and Child Health Assurance, Minnesota Department of Human Services

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical education (ACCME) through the joint sponsorship of the American Academy of Pediatrics and the AAP Minnesota Chapter. The American Academy of Pediatrics is accredited by the ACCME to provide continuing medical education for physicians. The AAP designates this educational activity for a maximum of 3.75 AMA PRA Category 1 Credit. Physicians should only claim credit commensurate with the extent of their participation in the activity. This activity is acceptable for up to 3.75 AAP credits. These credits can be applied toward the AAP CME/CPD Award available to Fellows and Candidate Members of the American Academy of Pediatrics. The American Academy of Physician Assistants accepts AMA PRA Category 1 Credits from organizations accredited by the ACCME. This program is approved for 3.75 NAPNAP contact hours of which 0 contain pharmacology (RX) content per the National Association of Pediatric Nurse Practitioners Continuing Education Guidelines.
Promoting Healthy Development Survey in Minnesota:
An assessment of the provision and quality of preventive and
developmental services delivered to Minnesota low income
children enrolled in Medicaid
By Dawn Brintnell, MPH and Susan Castellano, Minnesota Department of Human Services

Introduction
The Promoting Healthy Development Survey-PLUS (PHDS-PLUS) gathers information about the quality and type of preventive and developmental care young children receive. The PHDS-PLUS survey was developed by the Child and Adolescent Measurement Initiative (CAMHI) based at Oregon Health and Science University. Most questions are drawn from other national surveys (PEDS, NSLAITS, NSECH) and have been widely tested. It has been administered in at least 10 states in the past few years. The data presented represents a weighted sample of nearly fifty thousand (N=49,481) beneficiaries of Minnesota Medicaid who are continuously enrolled.

It was administered in Minnesota in 2004 as a telephone survey of 2000 Medical Assistance and MinnesotaCare parents of children ages 0-4. It was conducted only in English. The PHDS-PLUS assesses the provision and quality of preventive and developmental services including anticipatory guidance and parental education, assessment of parental health and well-being and safety within the family, assessment of parental concerns and follow-up with children identified as being at risk for developmental, behavioral, or social delays, family-centered care that promotes trust and partnerships with parents and identification of children with special health care needs.

Highlights of Survey Findings
Physician and ER visits
- Of the randomly sampled parents of children ages 0-4, nearly all of the children had a personal physician (92%). The overwhelming majority said they had visited a doctor’s office or clinic in the previous year (95%) for either a preventive and acute care visits.
- Of the parents who reported that their child has a personal clinician, about half (46%) reported that their child’s personal doctor was a pediatrician. A little more than a third of parents reported that their young child’s personal health care provider was a family practice physician (38%), and 3% reported that the provider was a nurse practitioner.
- A little less than half of the children (48%) had visited an emergency room at least once in the past year, and 14% had at least one overnight hospital stay according to parents. Not surprisingly, children with special health care needs were 3.3 times more likely than others to have an overnight hospital stay and 2.7 times more likely to have visited the emergency room.
- One of 10 children (9%) did not get needed care or care was delayed according to their parents. In half those cases (52%), the problem cited was a lack of available appointments with doctors or other health care providers. One-third (39%) of parents reported that this lack of availability had an impact on their ability to meet work and other daily responsibilities.

Health Status and Parent Concerns
PHDS-PLUS assesses the level and quality of comprehensive preventive and developmental care using a series of questions that measure the following six components:
- Provision of anticipatory guidance and parental education;
- Assessment of psychosocial issues and safety in the family;
- Smoking, alcohol, and substance use in the family;
- Provision of written and other health information to parents;
- Family-centered care (partnership with pediatric clinicians);
- Helpfulness of care provided.
A comprehensive care variable is created to measure the proportion of children receiving a basic or "threshold" level of care across all seven components of care called: "Basic Level of Preventive and Developmental Care."

**Proportion of Children Receiving a Basic Level of Preventive and Developmental Care in Each Area Assessed**

![Figure 1](image1)

Figure 1 shows the proportion of children who received the basic level of preventive and developmental care as defined by the survey across all components, as well as the score for each of the six components which make up the measure.

Pediatric clinicians were more likely to address issues related to the physical care of the child (49%) and injury prevention (50%) than to address topics related to the child’s development, behavior, and social growth (28%). When parents did receive anticipatory guidance and parental education, they were more likely to report fewer concerns about their child.

Figure 2 shows a substantial variation in comprehensive care received by race/ethnicity. Children of Hispanic ethnicity were the most likely to have received comprehensive care (35%), and Asian children were the least likely (10%).

**Basic Level of Preventive and Developmental Care for Several Measures, by Race/Ethnicity**

![Figure 2](image2)

**Coordinated Care**

- Thirteen percent (13%) of children under four years old met the definition of having a chronic condition or other special health care need likely to require ongoing and coordinated health care.

- Although many young children received care from multiple pediatric clinicians, that care was often not coordinated. One-third (34%) of parents reported that their child received care from more than one kind of health care provider or used more than one kind of health care service. Just over two out of five parents (44%) of children receiving care from more than one provider reported that no one from their child’s doctor’s office or clinic helped them to coordinate their child’s care.

- Surprisingly, children at risk for developmental or behavioral problems were significantly less likely to receive comprehensive services compared with those not at risk for such problems (11% vs. 27%). Children with a personal doctor or nurse were nearly twelve times more likely to receive comprehensive care compared with children without a personal doctor or nurse (24% vs. 2%).
One of five (19%) parents of young children had received information or counseling on the range of parent education and counseling topics recommended by the American Academy of Pediatrics to be routinely discussed. These included reading to children, nutrition, injury prevention, and child behavior and communication. However, one in two (49%) parents reported that their child’s pediatric clinician did not talk with them about one or more key topics but wished they had received information about these topics.

Parent information and counseling were helpful to parents. Nearly seven out of ten parents (67%) who received education and information from their child’s pediatric clinician reported that it was “very helpful” or “helpful” to them in building their knowledge and confidence as a parent in one or more areas, including understanding their child’s behavior, protecting their child from injuries, getting timely information about issues they are facing with their child, and helping them learn to meet their own needs while caring for their child.

As shown in Fig. 3, many parents had concerns about their child’s learning, development or behavior. More than one-third of parents (37%) said they were not asked by their child’s clinician whether they had concerns about their child’s development and well-being. Parents who were asked if they had concerns about the child were significantly more likely to get the information they needed compared with parents who were not asked (78% vs. 15%).

**Children’s Risk of Delay**

The survey found that the overall health status was excellent or very good for most young children enrolled in Medicaid in Minnesota (76%). However, one in four of the children (25%) were at moderate to high risk for behavioral, developmental, or social delays according to the PEDS screening tool imbedded in the survey.

Fig. 4 shows a strong correlation between children who were at greatest risk for developmental delays and parents with symptoms of depression. Additionally, parents who screened positive for depression were not more likely to be asked about depressive symptoms than those who did not (57% of parents who screened positive for depression were asked about depressive symptoms by their child’s clinician vs. 56% of parents who did not screen positive).
Family-Centered Care

Most parents considered care to be family-centered. Family-centered care was defined by the survey as how often the child’s pediatric clinicians: take time to understand the specific needs of the child, respect the parent as an expert about their child, explain things in a way the parent can understand and take time to understand the parent and child’s family and how the parent prefers to raise their child.

- Seven out of ten (68%) reported that their child’s pediatric clinician “usually or always” provided family-centered care in each of six areas. Parents who reported that their child had one personal doctor or nurse were significantly more likely to report receiving family-centered care as compared to children who did not have a personal doctor or nurse (32% vs. 71% vs. 49%).

- Parents of children at risk for developmental or behavioral problems were also significantly less likely to report receiving family-centered care as compared to children not at risk (54% vs. 73%).

- Parents who reported that care was family-centered were significantly more likely to have received anticipatory guidance and parental education (79% vs. 57%). Parents who reported positive experiences of care and communication with their pediatric clinicians were much more likely to report receiving preventive and developmental care in ways that addressed their questions and concerns.

Substance Use Assessment

Assessment of smoking, alcohol, and drug use occurred consistently. Three out of four (75%) parents reported being asked about smoking, alcohol, and drug use in the home. Almost all (91%) of parents reported being asked about smoking in the home, while 76% of parents were asked about alcohol and drug use. Pediatric clinicians were more likely to ask racial minorities than whites about smoking, alcohol, and drug use (78% vs. 72%) despite lack of evidence that these issues are more likely to occur among racial minorities.

Study Limitations

The mode and sampling biases likely lead to somewhat optimistic assessments of the health promotion and developmental services provided to the entire Medicaid population in the state. The survey was conducted only in English and therefore results do not represent the experiences of non-English speaking families and children.

Conclusions

Findings from the PHDS-PLUS survey reveal some significant successes as well as opportunities for improving the health of young children. Half of all children’s parents have concerns about their child’s learning, development or behavior. Many parents would like more information about their child’s development. Children who are at risk of delay are least likely to be screened. And parents with symptoms of depression are more likely to have children who screen as at risk of developmental delays.

Increase Developmental and Behavioral Health Screening and Reimbursement at your clinic....

Attend the Pediatric Developmental and Behavioral Health Screening and Reimbursement training on Saturday June 14, 2008 8am -Noon at The Depot, Minneapolis (see page 3 for registration). The session will cover:

- Introduction to pediatric developmental/behavioral screening;
- Minnesota Medicaid Coverage policy, reimbursement and measurement for developmental and mental health screening;
- How to approach a positive developmental/emotional/behavioral evaluation in the community;
- Understand how to talk with parents about screening results and parent concerns including preparing parents to accept referrals;
- Post-screening triage protocol to fit your practice and Information about local resources;
- A clinic panel discussing how screening, follow-up, and billing are handled in several Minnesota clinics.
In the spring of 2004, 11 pediatric practices from around the state came together for the inaugural session of the Minnesota Medical Home Learning Collaborative. The goal: to work together on improving the quality of care provided to children with special health care needs. Four years later, the group has grown to 23 practices, involving rural and urban pediatric practices, and one adult practice, from all around the state. The impact at the State Legislature has led to funding the initiative for three more years and plans to pay practices for Care Coordination for Medicaid patients.

The AAP 2002 Policy Statement defined the Medical Home and included these six operational characteristics: comprehensive, coordinated and family-centered, accessible, continuous, compassionate, and culturally effective with an identified primary care provider for children with special health care needs. The Minnesota Medical Home Collaborative Consensus Statement was developed by the participating providers, parents and care coordinators.

Medical Home teams include a physician (or other provider) champion, clinic staff and at least two parents of children with special health care needs. They meet weekly to monthly within the practice, working on small tests of change to develop care plans, improve telephone and scheduling protocols, create patient registries, make connections with schools and other community service providers, improve communication with specialists, and spread improvements to other providers within their practices and communities. Three times yearly, the teams meet Thursday evening and all day Friday to hear from national experts and learn from each other. The twenty-three teams in the Collaborative regularly survey families to determine if there is improvement in clinical outcomes for their children. They annually rate themselves using the Medical Home Index to measure practice improvements in six areas: parent-physician partnership support, decision support, delivery system design, clinical information systems, community outreach and organizational quality improvement.

As reported by parent survey, almost half of the teams have achieved a decline in emergency room visits and two thirds have fewer families reporting missed school and work days. Parents also note improvements in getting information over the phone and improved quality of time in clinic visits. All practices report improvements in their Medical Home Index scores over time. The personal benefit for the provider was summed up by Gordon Harvieux, MD, pediatrician and physician champion, “I personally have found that a small percentage of my patients take up a disproportionately large percentage of my time. Try as I might, I have always struggled to do a good job with their care. Medical Home has helped me greatly – both to manage my schedule, and provide better care!”

The 2007 Minnesota Legislature has been very interested in Medical Home, thanks in part to Mary Rahrick, MD, physician champion from Owatonna, and her Medical Home team, who testified at a House subcommittee on the benefits of Medical Home. The Legislature funded the Minnesota Medical Home Collaborative for three more years, previous funding having come from federal grants. The Minnesota Academy of Family Physicians has recently joined forces with Minnesota AAP to expand current efforts and add adults with chronic disease to those served. Nine of the Medical Home teams participated in a time study to determine how much non-reimbursed time is spent by providers and other clinic staff on care coordination. Jeff Schiff, MD, Past President of Minnesota AP and now Medical Director for Minnesota Department of Human Services, is currently heading a task force to determine criteria by which Minnesota Medicaid will provide payments to practices who provide care coordination services to their patients, based on the Medical Home model. This demonstration project will be the first of its kind in the nation.

Nationally, Medical Home is on the move as well. In 2007, the AAP partnered with three other primary care organizations to put forth the Joint Principles of the Patient-Centered Medical Home. These organizations, including the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians and American Osteopathic Association, represent 333,000 physicians. This coalition can help move forward the primary care Medical Home agenda within the national spotlight.

Primary care providers interested in forming teams/joining the Collaborative can contact Carolyn Allshouse, collaborative coordinator at (651)201-3653 or (800)728-5420.
From all accounts MN-AAP had a very good session this year, despite facing a state budget deficit of $935 million and fears near the end that health care reform would not be enacted. The MNAAP helped ensure medical home was incorporated into health care reform, passed major policy priorities including a Graduated Driver’s License for new drivers while avoiding most problematic legislation. Much of the credit for our success this year is owed to those pediatricians that are developing relationships with legislators and getting involved in the process. The Newborn Screening bill and the K-12 Education policy bill including a graduation requirement for physical education were vetoed by the Governor despite the hard work of members in contacting their elected officials.

Medical Home
Health Care Reform calls medical home “Health Care Homes” on a voluntary basis but with the intent they will be available to children and adults with chronic conditions. The legislation specifies what constitutes a health care home and it is very similar to the Medical Home Learning Collaborative of MNAAP. It specifies that a personal clinician or a primary care clinic may be certified as a health care home. If a clinic is certified, all of the primary care clinicians in the clinic must meet the criteria of a health care home. A “personal clinician” is defined as a physician, advanced practice nurse (APN), physician assistant (PA), or “other health care provider” as determined by the Commissioner of Health. Standards for certification of health care homes shall be developed/implemented by July 1, 2009 and must emphasize primary care. If initial savings from the health care home do not accrue, then the Commissioner of Human Services “may make recommendations to the legislature on reallocating costs within the health care system.” To address anticipated workforce shortages, the Commissioner of Health is directed to study changes needed in health professional licensing to ensure full utilization of APNs, PAs, and other professionals in the health care home and primary delivery system.

Increasing Access
Health Care Reform expands access to coverage by raising the income cap for families who are eligible for MinnesotaCare (MNCare) from $50,000 to $57,500, allows enrollees who fail to submit renewal forms to remain eligible for an additional month, and increases eligibility for adults without kids from 215% to 250% FPL. In an effort to enroll more eligible children, DHS is required to use data from the free and reduced school lunch program for the purposes of identifying children eligible for MA and the bill increases incentives to agencies who assist those enrolling in public programs from $20 to $25 per enrollee. Another component of Health Care Reform is ensuring continuity of care. The bill provides seamless coverage between MA and MNCare for children. A child whose family income rises above the MA limits may remain eligible for MA for two additional months and is automatically eligible for MNCare until renewal.

Other items passed as part of Health Care Reform bill which was signed by the Governor on May 29th include standardizing quality and care coordination incentives; a grouping system that arrays providers based on cost and quality of care; payment reform which will consider developing “baskets of care” and package pricing for coronary artery and heart disease, diabetes, asthma, and depression; recommendations on the design of an essential benefit set by January 2010; and provisions to increase continuity of care in public programs.

Graduated Drivers License and Passenger Safety
Legislative changes for teenage drivers were passed to address the fact that Minnesota has the highest rate of teen driving deaths in the country. A “Graduated Drivers License,” limits teenagers from driving between midnight and 5am (unless for work or school functions) and limited from having more than one other, non-family member in the vehicle for the first six months after they obtain their license. For the second six months they can have no more than three other non-family members in the vehicle. Unfortunately, the update to child restraint laws (booster seats) supported by MN-AAP did not pass- the Legislation passed the Senate but not the House to require children up to age eight to use booster seats when riding in a motor vehicle. There were also efforts once again to change our seat belt law to make it a primary offense to not wear a seat belt. The MN-AAP worked with the MMA, AAA, and the Minnesota Safety Council on these provisions.

 Continued on page 10
Help Wanted:

- **MNAAP Newsletter Editor**—Provide leadership in soliciting newsletter articles for on-line and print editions of the MNAAP newsletter; review content; work with MNAAP staff and Board to identify themes and topics for newsletter.

- **Youth Groups to assist with Newsletter and Mailings**—Nominate your favorite youth group to assist in assembling member mailings and newsletters. MNAAP will pay the organization for their service. The AAP–funded Healthy Tomorrows program Supporting Pan Asian Runaway and Homeless Youth assisted with newsletter assembly and mailing. A contribution of $200 from MNAAP was made to their organization to help support their continued advocacy and education in reducing teen runaways. They will have an exhibit at the MNAAP Annual Meeting. Thank you to Dr. Carolyn Levitt who has served as the program’s local sponsor.

- Anyone interested in more information about these opportunities should call 651-402-2056.

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**Plans for an Inborn Errors of Metabolism (IBEM) Information System**

Susan A. Berry, M.D., FAAP

Exciting plans are evolving for improving outcomes for children identified by newborn blood spot screening (NBS). We in Minnesota and other states in the Region 4 Genetics Collaborative have initiated studies for long-term follow-up of children with IBEM identified by NBS. Within the Region 4 Collaborative (Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, and Wisconsin), all seven states screen newborns using tandem mass spectrometry (MS/MS) to identify a number of rare, serious IBEM. Newborn screening by MS/MS is a relatively new technology first implemented by some states in 1998 that has been done in Minnesota since June 2001. Region 4 screens approximately 740,000 babies per year by MS/MS, resulting in an estimate of 265 cases confirmed with a screened IBEM each year (assuming an incidence of approximately 1:2800 for all IBEM combined.) While long-term follow-up is critical for monitoring health outcomes and evaluating the effectiveness of newborn screening, standards of clinical care for screened conditions have never been subjected to evidence-based study. More information about outcomes for these disorders is essential to a better understanding of the natural history of the conditions and development of best practice models for treatment.

Over time, we anticipate that disease registries will build the foundation for evidence-based medical practice and care for rare disorders ascertained through NBS because they will provide data to support treatment decisions based on larger cohorts of affected children than can be seen by an individual practitioner or specialty center. With the collaboration of multiple states over time, disease registries will have the power to provide a foundation for evidence-based medical practice and care for rare disorders ascertained through newborn screening.

To meet this challenge, in 2005 the Region 4 Long-term Follow-up and Clinical Outcomes Workgroup cooperated to focus on the initial diagnostic phase and long-term follow-up component of NBS by creating a disease registry to permit collection of accurate clinical data that could be used to assess outcomes and define the prospective natural history of these conditions. **Our concept is that by developing a core series of agreed-upon strategies and examination of the differences in treatment plans may yield evidence about optimal treatment choices.**

We received support for this effort with priority funding awarded to Region 4 from HRSA, the Health Services Research Administration, an agency of the federal Department of Health and Human Services. We are sequentially adding elements to ultimately allow follow up of all newborns identified by NBS as having IBEM with the goal of enrolling at least 90% of all affected children in our Region. We look forward to improving outcomes for all children diagnosed using this innovative new method.

Professor and Director, Division of Genetics and Metabolism, Department of Pediatrics University of Minnesota berry002@umn.edu

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**Public Policy Update continued**

**More work ahead in 2008-2009**

Continued work on the child booster seat bill in 2009 is needed. Also, we need to do a better job educating individual legislators on the topic of newborn screening. The Governor vetoed the newborn screening bill as a result of a strong push by privacy advocates to require that parents give informed consent prior to these tests being administered and the concern about opt-in versus opt-out.

So far, 12 House members announced their retirement following another contentious session. Eight are Republicans and four are Democrats. Members of the Senate are not up for re-election this year. MNAAP encourages members to become familiar with their elected representatives from the Minnesota House of Representative and Senate over the summer and provide advocacy for the child health issues that are important to your patients in your home district.

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Why participate in PROS? Two practitioners tell all

Burlington, Mass., pediatrician Ben Scheindlin, M.D., FAAP, does it for “the fun” and enjoys the knowledge that “colleagues all over the country are collaborating on the same effort.” Los Angeles pediatrician Heide Woo, M.D., FAAP, does it because it helps her provide “a higher quality of care” to her patients.

The “it” is participating in Pediatric Research in Office Settings (PROS) — the Academy’s practice-based research network. Along with 1,700 of their colleagues across the nation, Drs. Scheindlin and Woo help generate knowledge about the best pediatric care, not only for the patients in their offices, but also for those across the country. Dr. Scheindlin joined PROS in 1995, and all of his colleagues also participate in the research network. “The excitement of reading about and working on PROS studies spills over and constantly renews my excitement about primary care pediatric practice,” he said. “I get excited every time I see our practice name listed at the end of an article in a medical journal.”

Dr. Scheindlin said he has been able to use PROS research findings in his practice, including the normal time of pubertal onset in girls, the high prevalence of behavioral symptoms in young children and how to manage febrile young infants. PROS studies also have helped him rethink how he approaches well-child care and anticipatory guidance.

“As someone who has always been interested in research and attracted to academic medicine, but was called to clinical primary care practice, it’s great to have ready-made opportunities to contribute my small part to important research studies,” Dr. Scheindlin said. “I’m proud to be part of such a high-quality group as PROS. It’s a pediatric grassroots effort; it’s open to anyone who wants to participate, and it makes me feel more connected to the larger AAP.”

Dr. Woo practices with three colleagues, serving a diverse population in West Los Angeles. Since joining PROS in 1999, she has found that participation in studies affects her care of patients in surprising ways. “I have been asked by parents of boys coming in for physicals about when to expect the onset of puberty,” she noted. “I have been happy and gratified to tell them my part in the Secondary Sexual Characteristics in Boys study, which is designed to answer exactly that question, and that the answer will be available in the next year or two when the full study is complete.”

She also sees benefits with her practice employees. “The office staff who have helped us do the PROS studies have appreciated the fact that we as an office are committed to research and, through the research, also to improving the quality of care we deliver to the patients.”

Both practitioners have seen their roles in PROS grow over the years. Beginning as contributing practitioners, they have gone on to become chapter representatives and members of the network’s steering committee, and have participated in writing up study results (as any PROS practitioner is welcome to do).

Dr. Scheindlin co-authored a recently published paper in Clinical Pediatrics, based on the results of the violence-prevention-oriented Safety Check study. Dr. Woo co-authored a platform presentation at the 2004 Pediatric Academic Societies meeting, based on the results of the PROS Life Around Newborn Discharge study. “In the era of evidence-based medicine,” Dr. Woo said, “it is quite exciting to be able to prove the value of some of the things we do in general pediatrics, whether it is how we care for young febrile infants or the discus-sions we have with parents on anticipatory guidance and violence prevention.”

Core funding for PROS is provided by the Health Resources and Services Administration Maternal and Child Health Bureau and the Academy. As always, PROS seeks practitioners interested in participating in its research. To inquire about joining PROS, send an e-mail to pros@aap.org, or call PROS Central at 800/433-9016, extension 7623. Or you can contact the Minnesota PROS Coordinator, Ted Jewett, M.D. at 952/380-5164 or tjewett@slpeds.com

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- **Reducing Environmental Triggers of Asthma** – RETA project: MDH project to reduce environmental triggers of asthma shows significant cost savings and quality improvement. More information about the RETA project is available at [http://www.health.state.mn.us/asthma/documents/07retafactsheet.pdf](http://www.health.state.mn.us/asthma/documents/07retafactsheet.pdf). Erica L. Fishman, MSW, MPH Minnesota Department of Health Email: erica.fishman@health.state.mn.us PHONE: 651-201-5899 FAX: 651-201-5898.

- The Infant Developmental Inventory (IDI) and the Child Development Review Parent Questionnaire (CDR-PQ), Interagency Developmental Screening web pages: [www.health.state.mn.us/divs/fh/mch/devscrn](http://www.health.state.mn.us/divs/fh/mch/devscrn)

- **Reach Out and Read is a pediatric literacy program supported by MNAAP.** Over 48 participating clinics statewide reach over 37,000 Minnesota children annually. A special focus is placed on children growing up in poverty. Contact Lynne Burke, the Minnesota Coordinator at 612-873-8954 for information. [www.reachoutandread.org](http://www.reachoutandread.org)

Look for the **NEW and IMPROVED MN AAP website** in June 2008! Visit [www.mnaap.org](http://www.mnaap.org) for updates on Chapter activities, member profiles, a member directory, helpful links, public policy updates, CME opportunities and other pediatric resources.