

MCH Research Roundtable Webcast  
September 15th, 2004

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Chris DeGraw, M.D., M.P.H.  
Medical Officer, DRTE, MCHB  
Moderator

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M. Ann Drum, DDS, MPH  
Division Director, DRTE, MCHB  
Welcome

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Stella M. Yu, ScD, MPH  
Acting Chief, Research Branch, DRTE, MCHB  
Program Update

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**The Pediatric Emergency Care Applied Research Network (PECARN)**

Nathan Kuppermann, MD, MPH  
*For the PECARN Network*

MCH Research Roundtable  
September 15, 2004



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**What Is PECARN?**

- PECARN is the first federally funded national pediatric emergency medicine research network
- PECARN is funded through HRSA with the purpose of developing an infrastructure capable of overcoming inherent barriers to pediatric EMSC research
- PECARN provides the leadership and infrastructure to conduct collaborative multi-center research studies, and to encourage informational EMSC exchanges

*PECARN's ultimate goal is to conduct high priority multi-institutional research into the prevention and management of acute illnesses and injuries in children and youth of all ages*

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## Barriers to Research in PEM/EMSC

1. Low incidence rates of PEM adverse events
2. EMSC research typically conducted at tertiary care centers; most PEM visits occur outside of this setting
3. Complexity of obtaining informed consent in ED
4. Difficulty in tracking patients from out-of-hospital to hospital care
5. Difficulty in maintaining data quality and integrity in the ED setting
6. Lack of severity-adjustment and outcome measures
7. Historically, lack of funding for EMSC research

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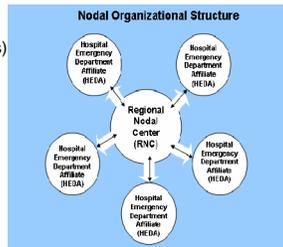
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## PECARN Structure

1. PECARN consists of four regional node centers (RNCs) located at diverse sites across the country
1. Each RNC hosts a regional network of hospital emergency department affiliates (HEDAs) for a total of 25 sites across the United States



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## PECARN Nodes

1. **Academic Centers Research Node (ACORN)**
  - University of California-Davis Medical Center, Sacramento, CA
  - Children's Hospital Medical Center, Cincinnati, OH
  - Children's Hospital of Wisconsin, Milwaukee, WI
  - Children's Hospital of Philadelphia, Philadelphia, PA
  - Primary Children's Medical Center, Salt Lake City, UT
  - St. Louis Children's Hospital, St. Louis, MO
2. **Chesapeake Applied Research Network (CARN)**
  - Children's National Medical Center, Washington, D.C.
  - Calvert Memorial Hospital, Prince Frederick, MD
  - Johns Hopkins Children's Center, Baltimore, MD
  - Holy Cross Hospital, Washington, D.C.
  - Howard County General Hospital, Columbia, MD
  - University of Maryland Hospital, Baltimore, MD

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## PECARN Nodes

3. **Great Lakes Regional Node (GLRN)**
  - University of Michigan, *Ann Arbor, MI*
  - Hurley Medical Center, *Flint, MI*
  - Spectrum Health System, *Grand Rapids, MI*
  - Marquette General Health System, *Marquette, MI*
  - Children's Hospital of Michigan, *Detroit, MI*
4. **Pediatric Emergency Department North East Team (PEDNET)**
  - Harlem Hospital Center, *Columbia University, Harlem, NY*
  - Bellevue Hospital Center, *New York, NY*
  - Children's Hospital of New York, *Columbia University, New York, NY*
  - Atlantic Health System, *Morristown Memorial Hospital, Morristown, NJ*
  - Children's Hospital of Buffalo, *Buffalo, NY*
  - Strong Memorial Hospital, *Rochester, NY*
  - Newark Beth Israel Medical Center, *Newark, NJ*
  - Upstate Medical University, *Syracuse, NY*

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## Structure of PECARN

- | The PECARN Central Data Management and Coordination Center (CDMCC), based at the University of Utah, manages data generated from the network under a cooperative agreement with MCHB

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## PECARN Strengths

- | 25 Hospital Emergency Department Affiliates
- | Serving ~ 800,000 acutely ill and injured children
- | Wide geographic and hospital representation
- | Senior-level expertise in epidemiology, statistics, health services research
- | Senior-level EMSC researchers and clinicians

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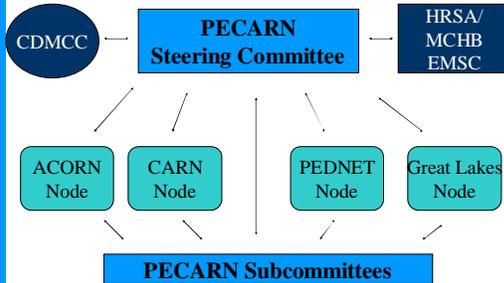
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## PECARN Administrative Structure



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## PECARN Steering Committee

- | Acts as the primary PECARN governing body
- | Equal membership from each node and the CDMCC
- | Responsible for reviewing and approving specific PECARN research proposals, formulating and monitoring policies guiding PECARN research activities
- | Establishes bylaws, policies, and procedures.
- | Establishes subcommittees to carry out specific tasks

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## PECARN Subcommittees



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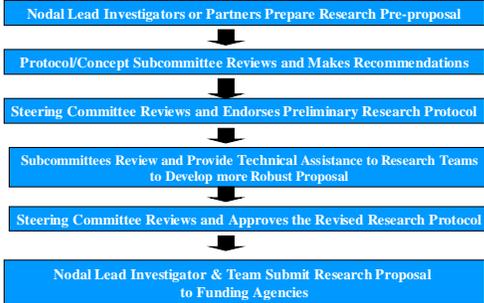
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## Proposal Intake Procedure and Work Flow



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## PECARN Research Projects



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### 1. PECARN Core Data Project Objectives

1. Describe the PECARN patient population
2. Determine availability, completeness, and agreement of core data from electronic and chart review
3. Test ability to collect, transfer, manage data from all sites
4. Establish benchmarking among sites
5. Examine racial disparities in pain management and asthma care
6. Examine practice pattern variation in management of *asthma* *long bone fractures*

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**2. Oral Dexamethasone for Bronchiolitis: an RCT**  
**Objectives**

- | To assess the effectiveness of oral dexamethasone for acute moderate-to-severe outpatient bronchiolitis in a multi-center randomized control trials with respect to
- | Have enrolled 200 patient to date
- | Anticipate completion in 2005

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**3. Hypothermia for Pediatric Cardiac Arrest**  
**Planning Grant**  
**Objectives**

- I. Describe cohort of pediatric patients after cardiac arrest from either outpatient or inpatient setting.
  - One year pilot data collection
    - | Patient characteristics
    - | Event characteristics
    - | Time intervals to outcomes
    - | Patient outcomes [survival, neurologic]
- II. Delineate factors associated with outcomes
- III. Characterize cohort eligible, and prepare for future RCT of hypothermia (or other) intervention

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**4. Childhood Head Trauma:**  
**A Neuroimaging Decision Rule**  
**Objectives**

- | To develop a clinical decision rule for the use of neuroimaging that identifies children at high risk and those at zero risk of TBI needing acute intervention after blunt head trauma
- | Long term goal is to identify the evidence on which to base appropriate ED evaluation of head-injured children

*Prospective data collection on ~ 22,000 patients with minor head injury (GCS 14 or 15), Started June 2004, ~ 5000 children enrolled to date*

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**5. Referral Patterns/Resource Utilization for Children Presenting with Mental Health Problems to the PED Objectives**

- | To ascertain the sources of referral into the institution for children with mental health issues
- | To ascertain the organization and utilization of resources used in the care of pediatric patients with psychiatric complaints and possible variation in these by PECARN site

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**6. Creating a Diagnosis Grouping System for Childhood ED Visits Objectives**

- | To develop a parsimonious diagnosis grouping system and a severity of illness classification system using ICD-9 codes for all childhood ED visits
- Will use data already collected from the PECARN Core Data Project
- Will use a formal expert consensus process to group diagnoses into clinically sensible categories
- **Goal:** 95% of pediatric ED diagnoses in 25-30 diagnostic groups

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**7. Bioterrorism Surveillance Objectives**

- | To develop and evaluate an information infrastructure for PECARN that creates an automated data stream of real-time clinical information from the EDs of PECARN hospitals to a data analysis center located at Children's Hospital of Boston
- | Data will be used for
  - | Bioterrorism surveillance
  - | General-purpose public health surveillance
  - | Clinical research

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## Other PECARN Projects

- I Many other PECARN projects under development and revision...
  - C-Spine immobilization
  - Short-term ED follow-up mechanisms after acute pediatric illness
  - Racial/ethnic health disparities
  - Management of status epilepticus

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## Future Goals of Network

1. To finalize and implement a formal research agenda to guide future research proposal development
2. To design and implement a plan to study/encourage the transfer of network findings to EMSC practices
3. To collaborate more closely with EMSC personnel, nurses, practitioners, and researchers in order to provide opportunities for bi-directional education and exchange of ideas, information and values between the treatment and academic communities

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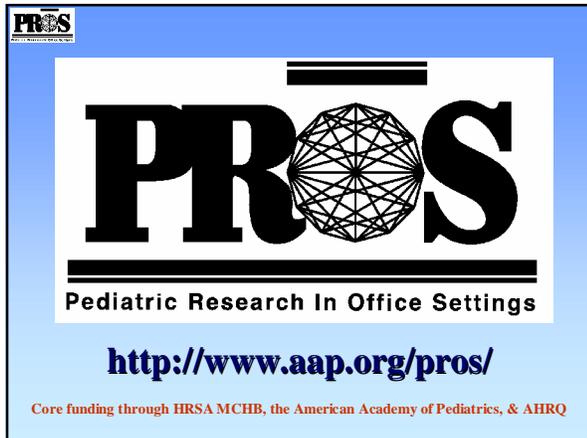
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**PROS**  
Pediatric Research In Office Settings

<http://www.aap.org/pros/>

Core funding through HRSA MCHB, the American Academy of Pediatrics, & AHRQ

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## Objective

- Briefly describe Pediatric Research in Office Settings (PROS), the national practice-based research network (PBRN) of the American Academy of Pediatrics

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## PROS Mission

To improve the health of children and enhance primary care practice by conducting national collaborative practice-based research.

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## Rationale Behind PROS Mission




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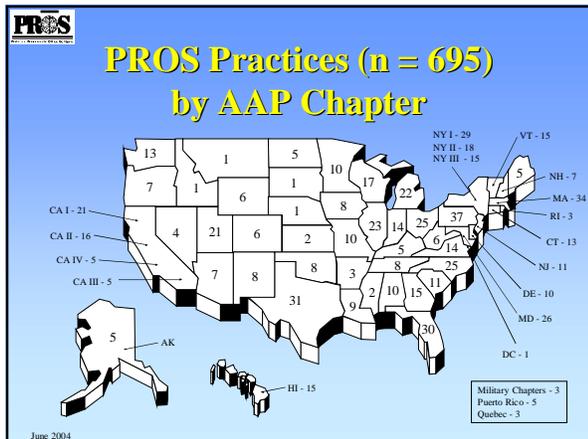
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**PROS Practitioners  
(n = 1,941)**

- ~ 1765 pediatricians (91% of PROS members)
  - ~ 5% of all AAP general primary care pediatricians
  - when compared to random sample of AAP general pediatricians
    - more males
    - older
    - more rural, equally urban, less suburban

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**Where Do PROS Practitioners  
Come From?**

- Participation is completely volunteer
- Recruitment
  - Word-of-mouth
  - Through articles about new studies in *AAP News* (monthly AAP newspaper)
  - As of 2004, all new AAP members receive PROS recruitment materials
- Practitioners need not be pediatricians, but at least one member of practice must be an AAP member

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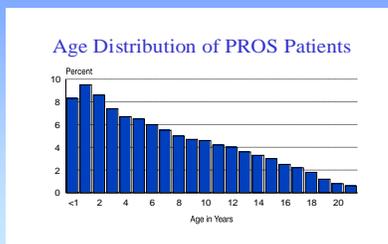
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## PROS Patients (~3.0 million)




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## PROS Patient Race / Ethnicity

- Estimates from some recent PROS studies
  - Polio Immunization Delivery Study
    - White: 71%, African-American: 12%, Hispanic/Latino: 11%
  - Life Around Newborn Discharge
    - 33% total minority
  - Defining Patient Visits
    - White: 79%, African-American: 9%, Multi-Racial 6%, Hispanic/Latino 13%

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## PROS Organizational Structure

- Practices, each with a contact practitioner.
- Chapter Coordinator & Co-Coordinator represent practices in AAP Chapter
  - meet twice a year to discuss new research and advise study teams
- Steering Committee determines policy
- PROS Research Staff in Elk Grove Village, IL
- Collaborating investigative teams from across U.S.

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## How a Research Idea Becomes a PROS Study

- Idea (from anyone) suggested to PROS leadership
  - 1/3 of ideas come from practitioners
- Proposal reviewed by Steering Committee
- Proposal reviewed by Chapter Coordinators
- Study funding sought and obtained
- Study conducted

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## Characteristics of a Study Appropriate for PROS

- Requires a geographically dispersed sample of patients and/or practitioners
- Requires a very large sample size or population base
  - uncommon condition
  - infrequent outcome

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## Characteristics of a Study Inappropriate for PROS

- Simple practitioner survey
- Data are proprietary
- Requires invasive procedures (this will likely change)

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## PROS Studies I

- Preschool vision screening
- Puberty in young girls
- Age-sex composition of pediatric practice
- Immunizations in pediatric practice
- Management of gastroenteritis
- Management of acute asthma
- Management of child psychosocial problems
- Febrile Infant Study
- Referrals in pediatric practice
- Polio Immunization Delivery
- Helping Improve Pediatric Practice Outcomes (Asthma)

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## PROS Studies II

- Life Around Newborn Discharge
- Randomized Controlled Trial to Prevent Child Violence\*
- Child Abuse Recognition Experience Study
- Learning from Errors in Ambulatory Pediatrics
- Defining Patient Visits
- Reducing Immunization Disparities\*
- Translating Immunization Research Into Practice\*
- Smoking Cessation in Pediatric Practice\*
- Reducing Environmental Tobacco Smoke\*
- Healthy Lifestyles\*

\* denotes intervention trial

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## Management of Very Young Febrile Infants

### Management and Outcomes of Care of Fever in Early Infancy

**Robert E. Piantelli, MD**  
**Thomas B. Newman, MD, MPH**  
**John Burrows, PhD**  
**Frank A. Stegman, MD**  
**John I. Takayama, MD, MPH**  
**Mark Siegel, PhD**  
**Stacy A. Fackel, MA**  
**Edward C. Wasserman, MD, MPH**

**Context:** Fever in infants challenges clinicians in distinguishing between serious conditions, such as bacteremia or bacterial meningitis, and minor illnesses. To date, the practice patterns of office-based practitioners in visiting febrile infants and the clinical outcomes resulting from their care have not been systematically studied.

**Objective:** To characterize the management and clinical outcomes of fever in infants, develop a clinical practice model for the identification of bacteremia/ meningitis, and compare the accuracy of urine testing.

**Design:** Prospective cohort study.

**Setting:** Offices of 227 practitioners from the Pediatric Research in Office Settings (PROS) network of the American Academy of Pediatrics in 44 states, the District of Columbia, and Puerto Rico.

**Patients:** Convenience sample of 3068 infants aged 3 months or younger with temperatures of at least 38°C seen by PROS practitioners from February 28, 1998, through April 25, 1998.

**Measurements and Main Results:** Management of fever in infants and outcomes of care were assessed in terms of the use of urine testing, antibiotic use, and hospitalization rates.

- Practitioners in office settings do not follow guidelines about the management of very young febrile infants (in this case, with respect to urine testing)
- No evidence of adverse short-term patient outcomes associated with failure to follow these guidelines

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## Why Do Pediatricians Participate in PROS?

- Curiosity about practice in general and their own practices in particular (practice-specific feedback provided after each PROS study)
- Altruism: a desire to contribute to child health research
- Desire for affiliation with others

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## What PROS Practitioners Say

“As a **PROS** pediatrician I can make a difference, not just for my patients but for all children.”

Columbia, South Carolina

“There has to be more to pediatrics than managing colds and flu. Participating in **PROS** allows a pediatrician in the trenches to directly impact the quality of health care for children through research.”

South Burlington, Vermont

“In an era where we tend to get bogged down with insurance and medical-legal issues, **PROS** studies bring back a sense of why I went into pediatrics.”

Rochester, New York

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## What PROS Practitioners Say

“Participation in **PROS** studies enables me to maintain my connection with the academic realm of pediatrics while contributing useful data to nationwide studies.”

Cranston, Rhode Island

“As a pediatrician in a rural county caring primarily for a poor, minority population, I often feel a sense of isolation. My participation in **PROS** connects me to the larger pediatric community. **PROS** helps me get through the day.”

Yakima, Washington

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## PROS Future

- More intervention studies
- More minority and disadvantaged subjects in PROS practices and in PROS studies
  - Continued collaboration with networks serving these groups
- More studies oriented towards practice systems and quality improvement

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<http://www.aap.org/pros/>

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**CARN:**  
*The Collaborative Ambulatory  
Research Network*

Jay Schulkin, Ph.D.  
Director of Research  
The American College of Obstetricians and  
Gynecologists

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## Introduction

- ✓ The American College of Obstetricians and Gynecologists (ACOG) was founded in 1951 in Chicago, Illinois. Currently based in Washington, DC, ACOG is a private, voluntary, nonprofit membership organization.
- ✓ ACOG today has over 47,000 members and is the nation's leading group of professionals providing health care for women.

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## Mission Statement

ACOG works primarily in four areas:

- ✓ Serving as a strong advocate for quality health care for women.
- ✓ Maintaining the highest standards of clinical practice and continuing education for its members.
- ✓ Promoting patient education and stimulating patient understanding of and involvement in medical care.
- ✓ Increasing awareness among its members and the public of the changing issues facing women's health care.

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## ACOG Members

- Ø Ninety-seven percent (97%) of obstetrician-gynecologists in the United States are members of ACOG.
- Ø There are several membership categories. Most members fall within the categories of Fellow and Junior Fellow.
  - Ø Fellows must be board-certified in obstetrics-gynecology.
  - Ø Junior Fellows must be currently participating in or recently graduated from an approved residency in obstetrics and gynecology.

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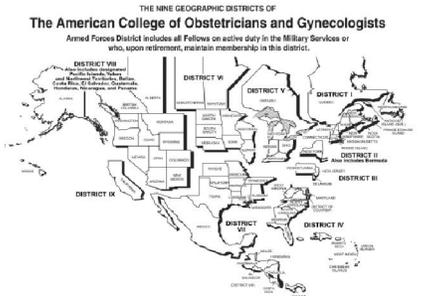
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ACOG is divided into ten districts consisting of nine geographic regions and the military.




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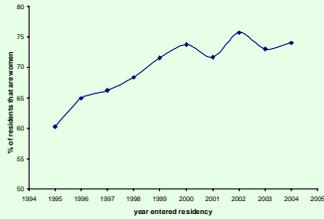
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### Changing Demographics of ACOG and OB/GYN

- Ø Men make up 57.9% and women make up 42.1% of ACOG membership, however, the number of women entering the field has increased substantially in the past decade.
- Ø The number of ethnic minorities also increased, but at a slower pace.




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### Collaborative Ambulatory Research Network (CARN)

**Who CARN is:**

- CARN members are practicing ACOG Fellows and Junior Fellows who volunteer to participate in ACOG research studies.
- There are currently over 750 CARN members, and we are actively working to expand our membership.
- Gender distribution: 60% male, 40% female.
- Median age for men is 52 years; median age for women is 46 years.
- CARN members are representative of each of 10 ACOG Districts.

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## CARN Study Objectives

- CARN studies focus on ambulatory care issues, and compare OB/GYNs' clinical practices to evidence-based guidelines produced by ACOG and other organizations.
- Results are used to develop better informed educational strategies, to disseminate information to physicians in areas in which a knowledge deficit is apparent, and ultimately to improve clinical practice and thus maternal and fetal health.

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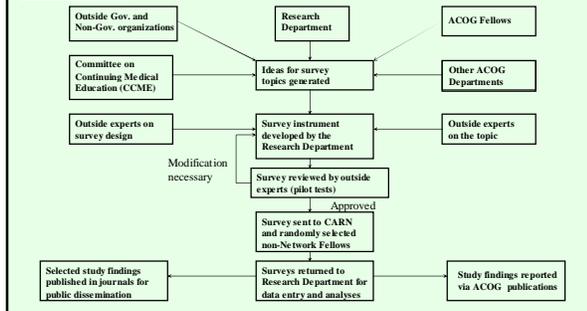
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## Study Logistics




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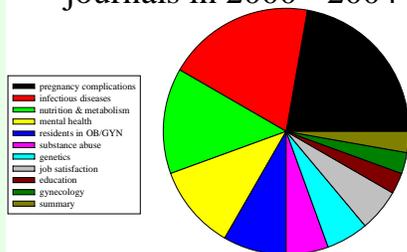
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36 papers generated by the CARN project have been published in peer-reviewed journals in 2000 - 2004




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## Cystic Fibrosis Preconception and Prenatal Screening

### Reasons for study:

- CF is the most common life-limiting autosomal recessive disease in Caucasians.
- Carrier screening and screening guidelines are now available for CF.
- CF carrier screening exemplifies issues in Maternal-Fetal Health amenable to preconception care and prenatal screening:
  - When, how, and to whom are physicians offering carrier screening.
  - What are physicians’ opinions, knowledge, and practices regarding screening.
- Thus, CF is a good model for studying preconception and prenatal practices with other heritable genetic disorders, such as Sickle Cell Anemia, Tay Sachs and Canavan disease.

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## CF Results Highlights

- Physicians were significantly more likely to inquire about CF history and offer carrier screening with pregnant than with non-pregnant patients.
- The majority of physicians were confident in their ability to interpret or handle a positive test.
- 66% of OBs offer carrier screening to **all** of their pregnant patients.
- 77% of physicians rated liability from not offering screening as a big concern.
- Physicians were deficient in deducing the relative risk of having a child with CF given parents’ carrier status.

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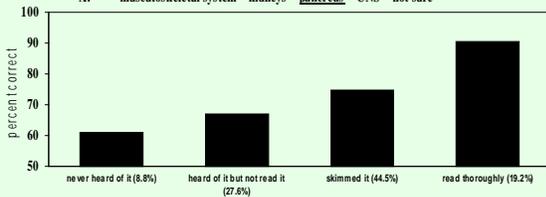
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The more familiar physicians were with the ACOG/ACMG screening guidelines for CF the more likely they were to answer knowledge questions correctly. For example:

Q: While the key to quality of life in CF is controlling lung disease, CF also affects the:  
A: musculoskeletal system kidneys pancreas CNS not sure




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## CF Conclusions:

- This study, conducted two years after ACOG/ACMG issued guidelines for CF carrier screening, has highlighted some of the concerns and advances in maternal-fetal health practices:
- Preconception screening for CF, which affords patients the widest range of options to avoid or reduce the risk of having an affected child, lags far behind prenatal screening.
- The majority of OBs offer screening to all patients regardless of selective criteria, possibly due to concerns with liability issues.
- Physicians rely most heavily on ACOG publications to stay informed about genetic screening related to pregnancy.
- Physicians who have read ACOG's guidelines are more knowledgeable about various aspects of CF and screening.

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## Neonatal Encephalopathy and Cerebral Palsy – current knowledge and the impact of ACOG documentation Reasons for Study:

- The causes of NE and CP historically have been poorly defined within the medical community, with causal misattributions leading to unwarranted obstetrical litigation.
- A 2001 ACOG survey study indicated knowledge gaps on issues of NE pathogenesis and histopathology by practicing OBs.
- ACOG produced and distributed a document (previous slide) on the pathogenesis and pathophysiology of NE and CP subsequent to ACOG's 2001 survey.
- To assess current knowledge of NE and CP and to determine the impact of this ACOG documentation on knowledge levels, we conducted a survey study in 2004 with knowledge questions identical to those in our 2001 study.

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## NE/CP Results Highlights

- OBs surveyed in 2004 performed better than OBs surveyed in 2001 on 10 of 15 knowledge questions.
- Physicians in 2004, similar to 2001, displayed knowledge gaps on the knowledge portion of the questionnaire.
- 11.6% of physicians reported reading thoroughly the ACOG/AAP documentation; 46.6% had skimmed it, and 41.7% had not read it.
- One third of physicians said their knowledge of NE was poor or deficient.
- The great majority of physicians said the training they received in NE during medical school, residency, and CME was inadequate to marginal.

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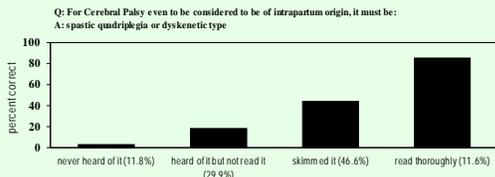
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The more familiar physicians were with the ACOG/AAP documentation on NE and CP, the better they were at answering knowledge questions correctly.

For example:




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## NE Conclusions

- This study was conducted 11 months after ACOG/AAP issued defining documentation on NE and indicates that there are substantial gaps in knowledge of NE and CP pathogenesis.
- There has been some improvement in knowledge levels since our 2001 study.
- Physicians who have read the ACOG/AAP document are more knowledgeable about various aspects of NE and CP.
- However, few physicians have thoroughly read this document.
- This study highlights the need for greater emphasis on NE and CP during training, and for documentation that physicians find more accessible.

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## Obesity and its impact on child and maternal health

- There is an epidemic of obesity in the United States
- Obesity is linked to increased risk for a number of diseases (e.g. hypertension, diabetes)
- Obesity complicates pregnancy and delivery
- Maternal obesity can affect later disease risk of the infants as adults

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## Results of the CARN study on OB/GYNs' views on the health risks of obesity

- Responding clinicians were knowledgeable concerning the links between obesity and disease risk
- They considered treating obesity in their patients to be an important part of their clinical responsibilities, and almost half believed that it would become even more important in the future
- They did not consider their training in medical school or residency to be adequate

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## A follow-up survey to the obesity study is being developed

- To examine systematically OB/GYN clinical practice regarding weight loss in their patients
- To examine in further detail OB/GYN knowledge regarding obesity and pregnancy and fetal/infant risk
- To examine to what extent OB/GYNs are encouraging their overweight/obese patients of child bearing age to lose weight prior to pregnancy – I.e. practicing preventive medicine

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## Ongoing Studies

- **Preterm delivery and low birth weight babies:** risk factors include nutritional deficiencies, infections, hypertension/preeclampsia, diabetes, race, obesity, substance abuse.
- **Post-dates:** There is variation among clinicians in management of women past their due date. This survey will document the variation with respect to initiation and methods of fetal testing, and timing and methods of induction.
- **Screening for Aneuploidy:** An assessment of the current techniques used to screen for Down Syndrome and other chromosomal disorders. We will also be contrasting physician knowledge and opinions on this topic with knowledge and screening for the less common heritable single gene disorders such as CF.
- **Spina bifida:** There has been some recent concern about the quality of information patients are receiving from obstetricians regarding outcomes for children with spina bifida.
- **Preconception Care:** This topic is relevant to the call for preconception genetic screening and many of the nutritional and lifestyle issues mentioned under preterm and which have been or will be surveyed by our department.

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## CARN and CME

- The articles published in peer-reviewed journals are a valuable resource for illustrating OB/GYNs' practice trends, knowledge strengths and gaps, opinions about developing technologies and trends, etc.
- In addition, every few years we produce documents summarizing the findings of the survey studies. OB/GYNs receive CME credit for familiarizing themselves with these review articles.
- CME courses may be selected and developed based on our findings, promptly addressing deficits in clinical practice and adherence to guidelines as they become apparent.
- Findings of each survey study are published in peer-reviewed journals, and are also described in ACOG newsletters and presented on ACOG's website.

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## Publications: 2004

- Diagnosing and managing thyroid disorders during pregnancy: A survey of obstetrician-gynecologists
- Professional liability and other career pressures: Impact on obstetrician-gynecologists' career satisfaction
- Heavier workload, less personal control: Impact of delivery on obstetrician-gynecologists' career satisfaction
- Resident performance on the CREOG in-training examination
- Knowledge, attitudes and reported practices regarding antibiotic prescribing for upper respiratory tract infections among obstetrician-gynecologists
- Management of diabetes mellitus by obstetrician-gynecologists
- Practice patterns of obstetrician-gynecologists regarding preconception and prenatal screening for cystic fibrosis
- Opportunities to reduce overuse of antibiotics for perinatal group B streptococcal disease prevention and management of preterm premature rupture of membranes
- Vaginal birth after cesarean delivery: Practice patterns of obstetrician-gynecologists
- Obstetrician-gynecologists' decision making about the diagnosis of major depressive disorder and premenstrual dysphoric disorder
- Physicians and depression: Personal and clinical
- Multiple pregnancy: Knowledge and practice patterns of obstetricians and gynecologists

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