

*Choosing the Best*  
**PEDIATRIC SPECIALIST**  
*for Your Child*



INDIANA  
**PERINATAL**  
NETWORK

**Y**our child is very special, and you want to make the best decisions for your child. This booklet is a guide to help you with these important decisions.

Today's health care system may seem very complicated. As the parent of a child with special health care needs, you are the "voice" for your child; your child's health care advocate. Your decisions, in partnership with your child's health care providers, about treatment plans and day-to-day care will help to improve your child's quality of life. *One of the most important decisions is choosing the right pediatric specialist: a health care provider who specializes in your child's condition.*

This booklet provides you with information to help you choose the right pediatric specialist for your child. It covers:

- Health Care for Your Child
- Choosing the Right Pediatric Specialist
- Types of Pediatric Specialists
- List of Questions for Choosing a Pediatric Specialist
- Working with Your Insurance Plan
- Sample Letters
- Resources for Your Family



## Making the Best Decisions

## Health Care for Your Child

Children have different health care needs than adults. Also, children require health care based on their ages and stages of growth—babies are different than five-year-olds. Children’s bodies and organs, as well as their learning abilities and their feelings, undergo different growth or “developmental” stages during childhood. Health care should be based on your child’s physical, mental, and emotional development.

All health care providers are not the same. When children become sick, most of their illnesses can be managed by their family physician or pediatrician (referred to as their “primary care physician”). The “medical home” includes a well-trained primary care physician (or team in the physician’s office) who provides for your child’s overall health care. The physician (or team) should know your child and family and should be a trusted partner in helping to make decisions.

Your child’s medical home should be:

- **Accessible**—Friendly; easy to reach by phone or by appointment. Accepts most types of insurance.
- **Comprehensive**—Offer care to meet most of your child’s common health care needs and coordinate care with other providers when needed.
- **Family centered**—Provide care based on the needs, beliefs and cultural background of your child and your family.



A small number of children have more serious health problems and need to see a pediatric specialist. You should work with your child's medical home to find a specialist(s) who has the training and experience to provide the best care. All health care providers, including the medical home and pediatric specialists, should work with you as a team to meet your child's health care needs.

*Pediatric specialists* have received more training in one specific area of medicine. They have experience in treating infants born too soon (*premature*), as well as toddlers and adolescents. Pediatric specialists are often the most up-to-date on current care and treatment and have special equipment and technology for diagnosing and treating children with conditions that are in their specialty. They know which tests or procedures are really needed. Pediatric specialists perform more pediatric procedures, and this experience often means a better outcome. Their understanding of child development may

prevent future health problems. Pediatric specialists work together with other pediatric specialists, therapists, dietitians, equipment suppliers, and others who might be needed to provide complete care for your child. All of these factors help to improve the health of your child while providing the most cost-effective care.



## Choosing the Right Pediatric Specialist

# Types of Specialists

COMMON NAME	PEDIATRIC MEDICAL NAME
Blood/Lymph Doctor	Pediatric Hematologist
Bone Surgeon	Pediatric Orthopedic Surgeon
Brain/Nerve Doctor	Pediatric Neurologist
Brain Surgeon	Pediatric Neurosurgeon
Cancer Doctor	Pediatric Oncologist
Developmental Doctor	Developmental Pediatrician
Diabetes/Gland/Hormone Doctor	Pediatric Diabetologist/Endocrinologist
Ear, Nose & Throat (ENT) Doctor	Pediatric Otolaryngologist
Eye Doctor	Pediatric Ophthalmologist
General Surgeon	Pediatric Surgeon
Heart Doctor	Pediatric Cardiologist
Heart Surgeon	Pediatric Cardiac Surgeon
Infectious Illness Doctor	Pediatric Infectious Disease Physician
Joint/Muscle Doctor	Pediatric Rheumatologist
Kidney Doctor	Pediatric Nephrologist
Bladder Doctor	Pediatric Urologist
Lung Doctor	Pediatric Pulmonologist
Rehab Doctor	Pediatric Physiatrist
Skin Doctor	Pediatric Dermatologist
Plastic Surgeon	Pediatric Plastic Surgeon
Stomach/Bowel/Liver (GI) Doctor	Pediatric Gastroenterologist
X-Ray Doctor	Pediatric Radiologist

Several kinds of specialists can be members of the team that cares for your child—including nurses, physicians and therapists. *Specialization* is the way in which a health care provider builds on a broad base of professional education and practice to develop more knowledge and skills in a certain area of practice. Below is information on the different types of providers.

## PHYSICIANS

*Family physicians* are specialists with advanced training in the care of all family members—from children to adults. *Pediatric specialists* are pediatricians with advanced training in the care of children. Pediatric specialists have received more extensive training in their area of practice. At left is a list of some of the different kinds of pediatric specialists.

## PEDIATRIC NURSE PRACTITIONERS (PNP) & CLINICAL NURSE SPECIALISTS (CNS)

*PNPs* and *CNSs* are registered nurses (RNs) who have completed a formal education program in the health care of children. PNP and CNS provide a wide range of health care services for children who are healthy or ill—from birth to early adulthood. They help children stay well and teach them and their families how to prevent illness. PNP perform physical exams, assess development, and manage common pediatric illnesses. Some PNP and CNS focus care on a specific group of children, specializing in a particular age, or a physical or emotional disorder or condition.



## **PEDIATRIC THERAPIST**

A licensed *pediatric therapist* has additional training and experience in both normal and *abnormal* (not normal) development of children. They understand disorders, diseases, disabilities, and injuries that may affect a child's development. Pediatric therapists spend most of their time performing *therapy* (treating the disease, disorder or disability) with children.

A pediatric therapist may also have special training or experience in a certain pediatric condition that can be helpful for your child.

Pediatric therapists include:

- *Physical Therapists*
- *Occupational Therapists*
- *Speech Language Pathologists*
- *Audiologists*

## **PEDIATRIC PHYSICAL THERAPIST**

Through the growing years, a *pediatric physical therapist* helps *gross motor* (general muscle) development, prevents *contractures* (shortening and thickening of muscles) and *deformities* (changes in shape) and improves movement.

## **PEDIATRIC OCCUPATIONAL THERAPIST**

A *pediatric occupational therapist* helps the development of *sensorimotor* control—the coordination of sensory information and motor skills—as well as *fine motor* (small muscle) development (eg. for putting on clothes, eating, etc.).

## **PEDIATRIC SPEECH LANGUAGE PATHOLOGIST**

A *pediatric speech pathologist* helps the child develop speech/language skills and *oral motor* (mouth muscle) skills for speaking and eating.

## **AUDIOLOGIST**

*Audiologists* help to prevent, identify and test hearing problems. They can perform hearing tests and find hearing problems in children—even at birth. They prescribe and provide hearing aids and other products; work with children who need services such as *auditory* (hearing related) training, speech-reading; and help to prevent hearing loss.

# Types of Specialists

# Questions to Ask When Choosing a Specialist

7

Questions you should ask when you choose a specialist for your child.

1. Did the specialist receive advanced training dedicated to the care of children?
2. Did the specialist complete advanced training (such as a fellowship) in his or her specialty?
3. Is the specialist's practice devoted to treating children?
4. Is the specialist board certified in his or her specialty?
5. In the last year, how many children did the specialist treat who were about the same age as my child and had a similar problem?
6. Is the specialist considered an expert in treating children with my child's condition?
7. If your child or grandchild was about the same age as my child and had a similar problem, would you want your loved one to be treated by this specialist.
8. I live in a rural area with limited resources. Where can I find specialists in the state who have special training and experience in treating my child's type of problem?
9. How will the specialist work in partnership and coordinate care with my family and medical home? Will the specialist be available to answer any questions or concerns?

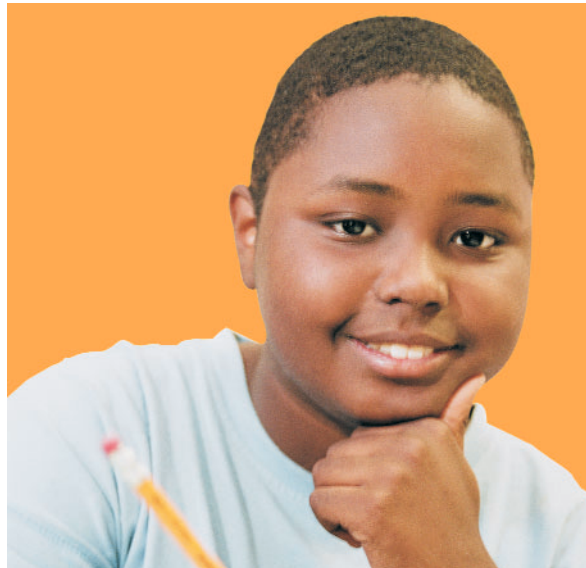


**S**everal different types of public and private health insurance plans help to cover the costs of services to children with special health care needs (examples include employer-sponsored group plans, individual health plans, *Hoosier Healthwise*, *First Steps*, and *Indiana Children's Special Health Care Services*). You and your pediatrician or family physician should gather information about the specialists included in your insurance plan. Pay attention to their pediatric training and how much of their practice is devoted to treating children. This will help you make an informed decision about the medical care your child receives.

If you do not think that the recommended specialist included in the insurance plan is qualified to treat your child, call your insurer to discuss your concerns. You should follow-up with a letter to the insurer (and your employer, if private insurance) so that your concerns are

in writing. Your pediatrician or family physician also should write to the public or private insurance plan (and employer, if appropriate) for you.

If you list good, solid reasons as to why the specialist in the insurance plan is not qualified to care for your child, the insurer might agree to cover the services of the specialist recommended by your child's doctor. *(See the sample letter on page 8 and refer to the questions on page 6.)*



## Working with Your Insurance Plan

# Sample Letter When Writing Your Insurer

9

[Date]

Insurer or Company Name  
Address  
City, State, Zip

Dear [representative's name or company],

My child, [name], is [age] years old and has [state your child's specific condition]. Our primary care doctor is [name of pediatrician/family physician] in [city]. Because of my child's medical problem, [he/she] was referred to [name of specialist] in [city].

*[Use paragraph below if the specialist is part of your insurance network, but not a doctor to whom your doctor normally refers.]*

[Name of specialist] is a member of your network, but is not the specialist our [pediatrician/family physician] normally refers to for this particular type of problem. I would like some information about [name of specialist] to determine [his/her] experience and expertise in treating children with [state your child's specific condition]. Please answer the following questions and return your response to me at the above address. *[include questions from page 6]*

*[Use paragraph below if your insurer denied coverage of the specialist to whom your child was referred.]*

[Name of specialist] is the specialist my child's [pediatrician/family physician] normally refers patients to because of [his/her] expertise in treating children with [state your child's specific condition]. I understand that [name of specialist] is not part of your network, but I believe [he/she] is the most qualified to care for my child because of [his/her] training and professional experience. I would appreciate your reconsideration of providing coverage for [name of specialist]. If you do not agree to provide coverage for [name of specialist], please consider a pediatric specialist within your network who has similar pediatric training and experience. I prefer my child be referred to a pediatric specialist rather than an adult specialist who only occasionally treats children.

Sincerely,

[Your Name]

[Date]

Specialist's Name  
Address  
City, State, Zip

Dear [name of specialist]:

My child, [name], is [age] years old and has [state your child's specific condition]. Our primary care physician is [name of pediatrician or family physician] in [city]. Because of my child's medical problem, [he/she] was referred to you.

As both a parent and health care consumer, I want the best and most appropriate care for my child. I would appreciate knowing more about your experience in treating children with [his/her] medical condition. Would you please answer the following questions [see list on page 6] and return a written response to me? If, in your opinion, you should not be the pediatric specialist who treats our child, we respect that judgement and request that you notify us and our insurer, [name and address of insurer], accordingly.

Your prompt response to my questions will help me make an informed and careful decision regarding my child's care by a specialist. Thank you for your time and assistance.

Sincerely,

[Your Name]

## Sample Letter When Writing to the Specialist

# Resources

**The Indiana Parent Information Network (IPIN)**—Helps parents, professionals and volunteers work together to support children with special needs. IPIN provides local, state and national resources by phone and mail to answer questions about disabilities, laws, health, education and social services by connecting families by phone and in person.  
800.433.0746  
4755 Kingsway Drive, Suite 105  
Indianapolis, IN 46205  
317.257.8683 or 800.964.IPIN  
[www.ai.org/ipin](http://www.ai.org/ipin)  
[FamilyNetwork@aol.com](mailto:FamilyNetwork@aol.com)

**Indiana Family Helpline**—Provides information (in English and Spanish), referrals, consumer education, advocacy and follow-up to callers on a variety of topics including obtaining early prenatal and child health care; accessing Medicaid and WIC providers; locating emergency housing, food pantries, utility assistance; and getting callers in contact with literacy, vocational and GED programs.  
800.433.0746

**Children's Special Health Care Services Indiana State Department of Health**—A supplemental health program that helps families of children with serious chronic medical conditions pay for treatment related to their child's condition with eligibility up to 250 percent of poverty.  
800.475.1355 or 317.233.1351 (IN)

**First Steps**—Indiana's early intervention system for infants and toddlers at risk for or with a development delay and their families.  
800.441.STEP  
[www.state.in.us/fssa/first\\_step/index.html](http://www.state.in.us/fssa/first_step/index.html)

**Hoosier Healthwise (Medicaid)**—Indiana's public health insurance program for children, pregnant women, and low-income families. Use this telephone number to enroll as well as to file a complaint or grievance.  
800.889.9949  
[www.in.gov/fssa/hoosier\\_healthwise/index.html](http://www.in.gov/fssa/hoosier_healthwise/index.html)

**Community Education & Child Advocacy Department**—Provides educational programs and materials that address children's health, wellness, injury prevention, disability awareness, and access to healthcare.  
Riley Hospital for Children  
575 West Drive, Room 008  
Indianapolis, IN 46202  
317.274.2964  
[www.rileyhospital.org/kids1st](http://www.rileyhospital.org/kids1st)

**The Arc of Indiana**—Advocates for people with mental retardation and related disabilities, and their families. The Arc of Indiana Master Trust allows a family member to leave funds to a loved one with a disability without endangering eligibility for government programs.  
800.382.9100  
[www.arcind.org](http://www.arcind.org)

**Pediatric Support Services**  
St. Vincent Children's Hospital  
317.338.3466  
[www.stvincent.org](http://www.stvincent.org)

**Indiana Department of Insurance**—Enforces statutes and regulations for private insurance companies including the handling of complaints/and the dissemination of public insurance information.

800.622.4461 OR 317.232.2385  
[www.in.gov/idoi](http://www.in.gov/idoi)

**Indiana Perinatal Network (IPN)**—An alliance of hundreds of individuals and organizations across Indiana who are committed to the belief that every baby in our state deserves to be born healthy and into a safe and nurturing home.

317.818.9486  
[www.indianaperinatal.org](http://www.indianaperinatal.org)

**American Academy of Pediatrics Referral Service**

[www.aap.org](http://www.aap.org)

**Physician-Patient Communications Network**

[www.medem.com](http://www.medem.com)

**National Association of Children's Hospitals and Related Institutions (NACHRI)**

401 Wythe Street  
Alexandria, VA 22314  
703.684.1355  
[www.childrenshospitals.net](http://www.childrenshospitals.net)

**American Speech-Language-Hearing Association**

—For help in finding an audiologist or speech-language pathologist who works with children of your child's age, try a search on the Web site. Click on the "Proserv" button and fill in the blanks for a list of certified providers in your area.  
[www.asha.org/about](http://www.asha.org/about)



## Resources

# “Choosing a Pediatric Specialist” Subcommittee

## “Choosing a Pediatric Specialist” Subcommittee Members

**Denise Arland**  
Parent

**Julia Brillhart, RN, MSN**  
Indiana Perinatal Network

**Debbie Carter**  
Pediatric Therapist

**Paula Farrell, MD**  
Neonatologist

**Maureen Greer**  
Emerald Consulting, Policy and Finance  
Consultant

**Darlene Kardatzke, MD**  
Developmental Pediatrician

**Cindy Lawrence**  
Pediatric Audiologist

**Ann Ruhmkorff**  
Pediatric Nurse Practitioner

**Richard L. Schreiner, MD**  
Chief, Riley Hospital for Children

**Sarah Stelzner, MD**  
Pediatrician

**Nancy Stone**  
Indiana Parent Information Network



# INDIANA PERINATAL NETWORK

[www.indianaperinatal.org](http://www.indianaperinatal.org)

The Indiana Perinatal Network (IPN) is an alliance of hundreds of individuals and organizations across Indiana committed to the beliefs that:

- Every mother deserves a healthy and safe pregnancy; and
- Every baby deserves to be born healthy and into a safe and nurturing home



*Funded by Title V through the  
Indiana State Department of Health  
Maternal and Child Health Services*



Indiana State  
Department of Health

April 2003

*We thank Riley Children's Foundation for  
supporting this booklet.*

**Riley Children's Foundation**  
Supporting Riley Hospital for Children • Camp Riley • Riley Museum Home