

## Neonatology Guide for Referring Physicians

DIVISION OF NEONATOLOGY

**EH** The Children's Hospital *of* Philadelphia<sup>®</sup>

chop.edu/neonatology



A MESSAGE FROM Division Chief Phyllis Dennery

### Dear Friend and Colleague,

I am pleased to provide you with information about the Division of Neonatology at The Children's Hospital of Philadelphia that will help you as you consider the care of your patients.

Our Division of Neonatology is committed to four key pillars of our mission: providing superb clinical care for infants with a multitude of complex diseases; conducting world-class research to further our understanding and care of these patients; training the next generation of neonatal care providers; and educating healthcare professionals and families.

Whether our nationally renowned neonatologists are providing state-of-the-art interventions, our surgeons are repairing congenital anomalies in neonates, or our Neonatal Follow-up Program is monitoring patients after hospitalization, we provide outstanding care for our patients from before birth well into childhood. Our expertise resonates beyond our own patient population — members of our care team regularly help create regional and national standards for neonatal care.

Now, as we continue to expand our collaboration among a network of area hospitals, we are able to extend this care to the most vulnerable infants at locations throughout the greater Philadelphia region. This allows us to partner with you and other referring physicians — for individual patient care and to develop optimal treatment strategies for the field as a whole.

With this brochure, we provide an overview of the neonatal programs and services we offer, and the team that provides them throughout the CHOP network. If you have further questions or would like to make a referral, we'd be delighted to talk with you.

Thank you for collaborating with us in the care of your patients.

Sincerely,

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#### INTRODUCTION

The Division of Neonatology, housed within one of the best pediatric hospitals in the nation, provides comprehensive Level IV care for critically ill newborns and premature infants. Our services include outreach, consultation, transport and inpatient intensive care.

We have more than 70 board-certified physicians who are leaders in the field, both clinically and in research. This team continues to make significant advances in the field of neonatal medicine and the care of the most fragile infants.

Patient volume at our Main Campus has grown to over 1,100 referrals per year, with more than a quarter of neonatal admissions coming from beyond the Philadelphia metropolitan area. Our team's clinical expertise is recognized by regional providers, as Children's Hospital now operates neonatal intensive care units at several community hospitals, and our division has garnered national recognition as one of the nation's top providers of neonatal care by U.S.News & World Report and Parents magazine.

#### The Harriet and Ronald Lassin Newborn/Infant Intensive Care Unit (N/IICU)

The N/IICU at Children's Hospital is a Level IV unit equipped with the latest technology and advances in neonatal medicine to provide care for babies with all types of conditions and surgical malformations. We provide care for neonates who need acute medical care, including multidisciplinary evaluation, complex surgical intervention, ECMO and special radiologic imaging. We also treat subspecialty patients who require the expertise of newborn intensive care staff and patients who are seeking second opinions.

Our unit cares for more than 1,100 babies each year. To meet rapidly growing demand, Children's Hospital is completing an expansion of the N/IICU. We have more than 83 beds and will be expanding to a total of 93 by 2015. Each new bed space will have more room and privacy for families.

Our family area provides additional comfort and convenience for caregivers with babies in the N/IICU:

- Lactation services and private breastfeeding rooms
- Sleeping rooms
- A family lounge with kitchen facilities
- A sibling play area
- Chaplain services available 24 hours a day
- A grieving room

Patients also benefit from the expertise of our team of nurses. CHOP has been designated a Magnet institution for nursing excellence by the American Nurses Credentialing Center.

#### Patient Safety in the N/IICU

Over the past several years, the N/IICU has worked towards a 50 percent reduction in bloodstream infections associated with central lines. This improvement is the direct result of an aggressive Hospital-wide campaign to promote thorough hand hygiene and less frequent handling of central lines. Led by our Director of Quality and Patient Safety, Jacquelyn Evans, M.D., we have also instituted monthly unit-based patient safety walk-rounds to provide a venue where staff and families can voice concerns and share best practices for safety.

#### **Neonatal Care Team**

In addition to board-certified attending neonatologists, we have a broad, experienced newborn care team that includes:

- Fellows
- Residents
- Physician assistants
- Neonatal and surgical nurse practitioners
- Clinical nurse specialists
- Staff and charge nurses
- ECMO specialists
- Respiratory care practitioners
- Social workers
- Dietitians
- Case managers
- Lactation consultants
- Director of psychosocial services
- Dedicated psychologist who cares for the developmental needs of older infants and provides counseling for families
- Centralized developmental care team (physical, occupational and speech therapists)
- Dedicated child life coordinator
- Family advocate

The N/IICU offers several services for families, including:

- Lactation consultation (available 24 hours a day)
- Ronald McDonald House to accommodate families overnight, with shuttle service
- Parent education/computer center (Connelly Resource Center for Families)
- Internet access in our family lounge
- Bereavement services

#### **Care Throughout the Delaware Valley**

In addition to care at our Main Campus, Children's Hospital neonatologists work at hospitals across the Children's Hospital Care Network, providing access to excellent neonatal services for families in every part of the Delaware Valley. Our neonatologists are in the intensive care nurseries at the Hospital of the University of Pennsylvania, Pennsylvania Hospital, Chester County Hospital, Doylestown Hospital, Holy Redeemer Hospital, Phoenixville Hospital, Grand View Hospital, University Medical Center at Princeton-Plainsboro, Virtua Voorhees and Virtua Memorial.



#### **SPECIALTY PROGRAMS**

The Division of Neonatology offers a variety of specialty programs and services to care for every condition a newborn might face.

#### Neonatal Airway Disorders Program

The Neonatal Airway Disorders Program is devoted solely to evaluation, treatment and follow-up care of all inpatient neonates and infants with complex airway issues. The program offers these infants seamless care, employing the newest and most innovative diagnostic and therapeutic modalities.

The program is housed within CHOP's N/IICU and led by pediatric otolaryngologists (ENT) with extensive experience treating infants with airway disorders. Our coordinated, multidisciplinary approach to specialized evaluation and treatment of these life-threatening conditions allows clinicians to communicate and work together easily so we can provide the most comprehensive, customized care for each child.

Our specialized team includes pediatric otolaryngologists, neonatologists, airway nurse practitioners, airway physician assistants, respiratory therapists, speech and feeding pathologists, pediatric audiologists, pediatric and interventional radiologists, social workers and case managers. The program also collaborates with other specialists and centers throughout CHOP to ensure infants receive the focused care they need. Patients benefit from around-the-clock access to experts in GI, Pulmonology, Anesthesiology and Critical Care Medicine, the Center for Childhood Communication Disorders, the Pediatric Feeding and Swallowing Center, Radiology, Allergy and Immunology, and the Sleep Center.

The team focuses on providing expert medical care for each patient, as well as emotional support for the entire family. The program provides extensive on-site counseling and pre-tracheostomy education to parents and caregivers by airway clinicians who are directly involved with each referral. Depending upon treatment, our program provides extensive follow-up of each patient in our Center for Pediatric Airway Disorders, including home technology, ventilation and tracheostomy care.



#### Newborn and Infant Chronic Lung Disease Program

Despite advances in neonatal care, bronchopulmonary dysplasia (BPD) also called chronic lung disease (CLD) — remains a major source of morbidity and mortality for extremely low birth weight infants. Currently there are no definitive treatments for CLD and only limited preventive strategies. A poor evidence base has led to large practice variations, and the safety and efficacy of many clinical practices currently used is unknown. In response to these challenges, CHOP has created an integrated, multidisciplinary program to assess, document and manage the medical needs of patients with CLD.

This is among the few dedicated programs in the nation devoted solely to treatment of infants with CLD. Housed within Children's Hospital's N/IICU, our program offers infants with CLD seamless care from evaluation through

treatment and long-term follow-up, employing the newest and most innovative diagnostic and therapeutic modalities available. Patients are evaluated using the most advanced imaging techniques, including CT angiogram, echocardiogram and pulmonary function testing. Our team formulates an appropriate treatment plan and offers the full range of therapeutic interventions.

The integrated team includes attending neonatologists, nursing champions, respiratory therapists, neonatal clinical pharmacists, neonatal nutritionists, physical and occupational therapists, speech therapists, case managers and a psychosocial support team. This program works closely with consultants from Cardiology, Pulmonology, ENT-Neonatal Airway Program and Endocrinology, and brings diverse expertise across different divisions at CHOP together. Our coordinated, multidisciplinary approach to evaluation and management of this life-threatening disease allows clinicians to communicate and work together easily so that we can provide the most comprehensive, customized care for each child.

Our focus is providing lifesaving therapy without compromising long-term quality of life. When treatment in the intensive care setting is no longer needed, the team facilitates the transition to home, home hospital or chronic care facility. In addition to high-quality patient care, this program also promotes collaborative research in an effort to provide evidence in areas of controversy and promote evidence-based practice in this disease.



#### Neonatal Craniofacial Program

The Children's Hospital of Philadelphia Craniofacial Program — located within the Division of Plastic Surgery — is one of the largest centers of its kind. Due to increased referrals to the program and its scope of expertise in the diagnosis and treatment of the neonate, we created the Neonatal Craniofacial Program, a specialized entity dedicated to diagnosis, treatment and follow-up of neonates with rare and complex disorders of the cranium, face and mandible.

This program consists of a multidisciplinary team of highly specialized, board-certified neonatologists, plastic surgeons, geneticists, otolaryngologists, pulmonologists, feeding/speech therapists, nurse practitioners and physician assistants. Specialists from Dentistry, Ophthalmology, Interventional

Radiology, Orthodontics, Neurosurgery, General Pediatric Surgery, Dermatology and Oculoplastic Surgery are also available for consultation and care, when needed.



The program specializes in complex craniofacial neonatal disorders and syndromes such as craniosynostosis, and vascular malformations of the face, limb and scalp. The team works closely with CHOP's Center for Pediatric Airway Disorders, Technology Dependence Center, Cleft Lip and Palate Center, Facial Motion Disorders Clinic, Center for Childhood Communication and Audiology, Pediatric Feeding and Swallowing Center, 22q and You Center, and the Vascular Malformation Center to coordinate any necessary surgery and follow-up care.

Early diagnosis and treatment is necessary for optimal outcome and correction of many craniofacial birth defects. The program evaluates babies ideally within the first few weeks of life and is equipped to provide comprehensive craniofacial and airway evaluations, including sleep studies and fluoroscopy-swallow studies. An infant in need of surgery

benefits from some of the most experienced neonatal-pediatric craniofacial surgeons in the United States who employ the most advanced reconstruction techniques. Our team also works closely with our Neonatal Airway Program in coordination of procedures, surgery and follow-up care.

The program has developed specific expertise in severe micrognathia, dealing solely with neonatal airway and tongue-based obstruction and offering promising treatments such as mandibular distraction osteogenesis. Our pediatric plastic surgery team works directly with neonatal airway surgeons in planning for and collaborating during surgery on such patients. The team is often able to provide alternate treatments to a tracheostomy in these patients and works closely with our Neonatal Airway team for diagnosis, treatment, follow-up and transition to home.

#### Neonatal Stroke Program

The Neonatal Stroke Program is part of Children's Hospital's Stroke Program and provides specialized treatment for newborns with stroke during their initial illness and over long-term neurologic and developmental follow-up. The program includes a team of core physicians from Neurology, Neuroradiology and Neurosurgery. Additional experts from Hematology, Cardiology and Genetics/Metabolism are consulted as needed. Support staff includes a dedicated social worker, nurse, education coordinator and neuropsychologist.

Any full-term neonate with seizures or depressed consciousness may have had a stroke. There are three types of neonatal stroke: arterial ischemic (due to blockage of blood flow in an artery), venous thrombosis (due to clot in veins of the brain), and hemorrhagic (due to bleeding in the brain). Within 24 hours of admission, infants with suspected stroke who are transferred to CHOP are seen by neurologists on the ICU consultation service who work closely with the stroke team neurologists and support staff throughout the Hospital stay. All medical care during the Hospital stay is coordinated by the N/IICU staff.

Infants typically undergo continuous video EEG monitoring to guide treatment of seizures, followed by a brain MRI to confirm the diagnosis and guide additional diagnostic testing. The Stroke Program provides outpatient follow-up in a multidisciplinary clinic tailored according to the needs of each individual child at each stage of their development. The clinic team includes a stroke neurologist, social worker, nurse, education coordinator, neuropsychologist, physical therapist, occupational therapist and speech therapist.

Many infants and families are invited to participate in observational stroke research studies to improve knowledge of the causes and treatments for neonatal stroke. Additional help for families is available through a very active Stroke Family Support Group.



#### Neonatal Follow-up Program

For more than 30 years, the Neonatal Follow-up Program at Children's Hospital has cared for preterm and high-risk infants after their discharge from the Hospital. The program uses an interdisciplinary approach to provide assessment and care coordination for children's medical, nutritional, neurological, developmental and psychosocial needs during the early childhood years. The program provides families with information, education and support and recommends community services that may address a child's specific needs. The staff also works in coordination with primary care providers to meet the needs of preterm and high-risk infants.

#### Special Babies Clinic

The Special Babies Clinic (SBC) is the developmental follow-up clinic for high-risk infants born at the Hospital of the University of Pennsylvania, which is adjacent to CHOP.

The SBC provides medical and developmental evaluations of babies from 3 months to 5 years of age. While the SBC evaluates babies and families cared for by primary care providers (PCPs) both within and outside of the CHOP system, the use of electronic health records promotes seamless care coordination with those PCPs and subspecialties within the CHOP system.

The SBC emphasizes early literacy through modeling reading and distributing books at every visit as part of CHOP's Reach Out and Read Program. In addition, Special Trips for Special Babies — a program made possible through the generosity of the Philadelphia Zoo and the Please Touch Museum — provides free summer SBC group trips to the zoo or the museum.

#### Pulmonary Hypoplasia Program

The Pulmonary Hypoplasia Program is a multidisciplinary follow-up program established to manage the unique medical and surgical needs of patients with pulmonary hypoplasia. The most common diagnoses are congenital diaphragmatic hernia (CDH) and congenital cystic adenomatoid malformation (CCAM), but may also include giant omphalocele, congenital chylothorax and other lung malformations.

Services include:

- Coordinated care in the N/IICU by a core group of nurses, neonatologists and surgeons
- Consultation with Cardiology, Developmental Care, Gastroenterology, Nutrition, Ophthalmology, the Pulmonary Hypertension team and Social Work while in the N/IICU, and ongoing care after discharge through the school years
- Infant pulmonary function testing
- Three-dimensional cardiovascular and pulmonary imaging laboratory (CT angiogram, MRI)
- Pulmonary hypertension therapeutics, including interventional cardiac catheterization and pulmonary arterial vasodilator therapies
- Coordination with Cardiac Center, Center for Pediatric Airway Disorders and Home Ventilation Program

#### Psychosocial and Developmental Services

Having a newborn or infant sick and in the hospital is a scary experience for families. As one of the nation's leading N/IICUs, we have a dedicated director of Psychosocial Services who works in conjunction with the supporting psychosocial and developmental services we offer. This specialist works collaboratively with Chaplaincy Services, the Child Life, Education and Creative Arts Therapy Department, Lactation, Occupational Therapy, Physical Therapy, Speech and Language Pathology, the Nursing Department, the Psychology Department, and Social Work to develop systems and programs that expand access to resources and information for families and improve communication between staff and families.

We offer comprehensive psychosocial and developmental services for babies and their families. These services help parents feel more comfortable with their baby and help babies progress in their growth. We encourage families to ask questions to find out more about how they can bond with and care for their baby during the hospitalization. The following specialists are available to work with parents in the N/IICU:

- Chaplains offer spiritual care including prayers, rituals, sacraments and practices of individual faith groups.
- Child life specialists and art and music therapists work with the family to find creative ways to assist with bonding.
- Lactation/breastfeeding specialists can discuss breastfeeding and, if desired, help mothers maximize milk production.
- Occupational therapists, physical therapists and speech-language pathologists support parents in their interactions with their baby. They will teach parents to recognize cues and behavioral signals of their baby.
- Psychologists and social workers serve as links to the medical team, helping parents express their feelings
  and bond with their baby, and connect parents with additional resources at the Hospital and back home.

#### Neonatology-Surgery Service

The Divisions of Neonatology and General Surgery have created a unique team devoted solely to the care of the newborn infant with a surgical diagnosis. These highly complex infants have both a Neonatology and Surgery attending involved every day in the evaluation and treatment plan. This successful endeavor has led to a seamless multidisciplinary approach to the care of infants with birth defects such as congenital diaphragmatic hernia, giant omphalocele and other serious malformations that need surgical intervention.

#### **ECMO Program**

Our Extracorporeal Membrane Oxygenation (ECMO) Program is one of the most active and expert in the country and has been designated a Center of Excellence by the Extracorporeal Life Support Organization (ELSO). Our team strives to provide the best, most vigilant care to every patient through rigorous training, expert leadership, and a deep commitment to self-evaluation and improvement.

Each year, approximately 50 to 60 neonates and children are supported with ECMO in our hospital, 45 percent of those in our Newborn/Infant Intensive Care Unit. Our team has completed nearly 1,000 ECMO runs since the program opened in May of 1990.



The program is led by a board-certified general and thoracic pediatric surgeon, and a registered respiratory therapist additionally certified as a neonatal pediatric specialist. Our ECMO Operations Committee — made up of a neonatologist, pediatric anesthesiologist/intensivist, cardiologist/intensivist, and program director and manager — convenes monthly to review cases, compare our complication rates against the international summary ELSO data, and evaluate potential process improvements.

Our ECMO core team consists of more than 20 trained R.N.s and R.R.T.s. An in-house ECMO specialist and ECMO resource M.D. are available to staff 24/7 as well. One ECMO clinical specialist is with each pump and one bedside R.N. is with each patient at all times. A wide range of specialties are also on call at all times, including Cardiology, General Surgery, Cardiovascular Surgery, Neonatology, Anesthesiology, Neurosurgery, Interventional Radiology, Genetics, Biomedical Engineering, Social Work, Neurology, Nephrology, Critical Care, Pulmonology, Hematology/ Oncology, Infectious Disease and Gastroenterology.

The program constantly evaluates data and cases, communicating learnings to specialists and ECMO physicians promptly and changing procedure when needed.

#### Breastfeeding and Lactation Program

Our lactation team is comprised of international board-certified lactation consultants and trained breastfeeding resource nurses who provide optimal care based on extensive research and many years of experience. The team is world-renowned for work with medically fragile children and their mothers and has participated in numerous national studies, received research grants, and written and lectured extensively. The team provides one-on-one breastfeeding consultations and is available 24 hours per day, 7 days per week. We offer electric breast pumps and private pump rooms.

Our new state-of-the-art Human Milk Management Center helps ensure that infants receive optimal nutrition through human milk during their hospitalization. The center is staffed by trained milk technicians who work with lactation specialists to develop a plan of care for babies with special needs. The center can provide a variety of services to mothers of hospitalized babies, including: human milk management, skim milk, fractionation of human milk, human milk analysis and donor milk. For mothers not able to provide enough milk for their baby or who choose not to pump, donor milk is the next best thing. Lactation consultants and breastfeeding resource nurses can also address any breastfeeding concerns or challenges.

#### **OTHER SPECIALTY SERVICES**

Other CHOP specialty programs with expertise in the treatment of newborn and infant conditions include:

#### Intestinal Rehabilitation Program

Short bowel syndrome and intestinal failure occur when the intestine is not long enough or doesn't work well enough to absorb nutrients. Short bowel syndrome is often caused by surgical removal of part of the intestine due to necrotizing enterocolitis (NEC), intestinal atresia or gastroschisis; whereas intestinal failure may result from a wide variety of congenital diseases.

Infants with these conditions are managed by our specialized Intestinal Rehabilitation Program (IRP), which includes a gastroenterologist, dietician, nurse and social worker. Members of the team collaborate with neonatologists, surgeons and other providers to develop a regimen that is tailored to the child's unique condition and anatomy. In most cases, the right combination of diet and medications can be established to rehabilitate the intestine and improve its ability to process nutrients. The IRP team continues to follow children after discharge from the Hospital to maximize continuity of care, monitor growth, oversee vitamin and mineral supplementation, and help to ensure that special needs related to the child's intestinal condition are met in the home and in school.

In severe cases, infants with short bowel syndrome or intestinal failure may require prolonged treatment with intravenous nutrition, which can result in liver damage. The IRP team monitors infants for signs of liver disease and implements a variety of strategies to limit damage. Certain children with signs of advanced liver disease may be eligible to receive Omegaven<sup>®</sup>, which is an alternative intravenous lipid emulsion that has been associated with decreased signs of liver damage in preliminary studies. The IRP team participates in an expanded access Investigational New Drug (IND) protocol through the FDA that allows us to offer Omegaven to children at CHOP who meet specific protocol criteria.

#### Neonatal Ophthalmology

In addition to offering retinal and oculoplastic surgery to address conditions including congenital cataracts, the neonatal team works closely with the Division of Ophthalmology at CHOP to address retinopathy of prematurity (ROP). The team provides diagnostic examinations, digital retinal imaging for documentation and diagnosis, and laser treatment for at-risk infants in the N/IICU, as well as consultation and treatment for patients referred from other centers. Long-term management of ROP — as well as strabismus, refractive abnormalities and other late visual complications of prematurity — is coordinated by the Division of Ophthalmology in outpatient offices in Philadelphia, Exton, King of Prussia and Chalfont in Pennsylvania, and Princeton and Voorhees in New Jersey.

#### Congenital Hyperinsulinism Center

The Congenital Hyperinsulinism Center team incorporates Endocrinology, Surgery, Pathology and Nuclear Medicine Radiology to care for children with this condition. All neonates referred for hyperinsulinism (HI) are admitted to the N/IICU and cared for by the Neonatology-Surgery team with close monitoring by Endocrinology.

CHOP is the only pediatric medical center in the U.S. that uses 18F-DOPA PET/CT under a research protocol to detect a focal lesion of congenital hyperinsulinism prior to surgery. It is a minimally invasive imaging tool that has been found to be highly accurate at detecting and localizing a focal lesion. The test allows surgeons to determine, before they operate, whether they can potentially cure babies with severe insulin problems without leaving them susceptible to diabetes.

#### Infantile Hemangioma

Our care of infantile hemangioma incorporates subspecialty services from Dermatology, Cardiology, Neurology, Ophthalmology and Oculoplastic Surgery, Otolaryngology, Plastic Surgery, and Radiology (Interventional) in association with Neonatology and General Pediatrics. All neonates referred for inpatient initiation and rapid up-titration of pharmacologic therapy with agents such as beta-blocker or corticosteroid are admitted to the N/IICU and cared for by the Neonatology team with close monitoring by Dermatology.

Older infants and children may be admitted to a dedicated inpatient ward with experience managing children with hemangiomas. Children's Hospital utilizes a standardized inpatient protocol for evaluating and managing this condition so that babies needing rapid pharmacologic intervention can be treated in a safe and closely monitored setting.

#### **Genetics Services**

The Division of Human Genetics and Molecular Biology at CHOP offers world-renowned, state-of-the-art services in the areas of clinical and molecular genetics for neonates, as well as genetic counseling for families. The Division includes a Clinical Genetics section, the "22q and You" Center for children suspected or diagnosed with the 22q11.2 deletion syndrome, and two full-service testing laboratories for cytogenomics and molecular genetics.

#### **Clinical Genetics**

The Clinical Genetics section offers a specific genetics clinic for patients with hearing loss, both isolated and syndromic, as well as a clinic for syndromes involving overgrowth, skeletal dysplasias, cleft lip and palate, craniofacial disorders, multiple congenital anomalies, and chromosomal aneuploidy. The "22q and You" Center is a multidisciplinary clinic and the largest program in the nation specializing in children and adults with a chromosome 22q11.2 deletion, a condition often diagnosed in the N/IICU.

The Division's team includes physicians, genetic counselors, a Ph.D. nurse practitioner and support staff, and works closely with neonatologists, social workers, physician assistants, nurse practitioners and nurses to provide a comprehensive plan of care and follow-up. In addition, the team works hand-in-hand with CHOP's Special Delivery Unit, the world's first birthing unit for pregnancies diagnosed with birth defects, both before and following delivery.

#### **Biochemical Genetics/Metabolic Disease**

Our Biochemical Genetics/Metabolic Disease section provides diagnostic and treatment services for inborn errors of metabolism including:

- Organic acidopathies
- Aminoacidopathies
- Fatty acid oxidation defects
- Mitochondrial and peroxisomal disorders
- Lysosomal storage and connective tissue disorders
- Urea cycle defects and all other inborn errors of metabolism

The team includes physicians, nurse practitioners, social workers, genetic counselors and dieticians, as well as Metabolic Diagnostic Laboratory staff who provide consultation and discuss the results of metabolic tests with physicians and families.

#### Technology Dependence Center/Home Ventilation Program

Often, a patient in the N/IICU requires a tracheostomy and mechanical ventilation for treatment of severe airway or lung disease. The Technology Dependence Center (TDC)/Home Ventilation Program cares for infants and children with chronic lung disease who need assistive therapies such as mechanical ventilation, airway clearance devices or an artificial airway. Such technologies, used appropriately, can allow better growth and development and decrease the need for hospital care. The TDC assesses and treats conditions including chronic respiratory failure and insufficiency in patients with bronchopulmonary dysplasia, neuromuscular disease, genetic or metabolic disorders, and airway anomalies. The team includes physicians, advanced practice nurses, nutritionists and social workers. The goal of the TDC is to coordinate and manage equipment and home nursing needs, and collaborate with other healthcare providers.

#### Center for Fetal Diagnosis and Treatment

The Center for Fetal Diagnosis and Treatment is one of only a few programs in the world to offer technologically advanced, multidisciplinary care for unborn babies with genetic or anatomical abnormalities. Our comprehensive services range from prenatal diagnosis and surveillance to fetal therapy and open fetal surgery. The Center has also created the Garbose Family Special Delivery Unit, the world's first delivery unit within a pediatric hospital exclusively for women carrying fetuses with known birth defects. To date, the program has received more than 12,500 referrals from all 50 states and 56 countries.

#### Neonatal Palliative Care

Sadly, there are times when the burdens of disease exceed the limits of available technology. The Division of Neonatology has a framework for providing compassionate and comprehensive care to infants with lifelimiting illness. An active nursing bereavement committee focuses on effectively supporting a family whose infant is dying. In addition, the N/IICU has a strong affiliation with the Hospital's palliative care team, known as the Pediatric Advanced Care Team (PACT). PACT is a multidisciplinary group that assists families with decision making, provides a bridge to bereavement services, recommends therapies to relieve symptoms, provides emotional and spiritual support to patients and their families, and helps arrange for hospice support, if necessary. Our goal is to support families as they face the unimaginable and help them start down a path of healing.

#### Neonatal Neurology Program

Neuromuscular

CHOP's Division of Neurology has expanded services to provide a comprehensive evaluation for the infant with severe hypotonia or neuromuscular disorders. Dedicated, specialized neurologists evaluate these infants and perform sophisticated testing such as high-resolution muscle ultrasound, EMG and muscle biopsy. Collaboration with Neuropathology, Neuroradiology, and Genetics and Metabolism is an integral part of this vital program. Physical, occupational and speech therapists with expertise in pediatric neuromuscular disorders provide comprehensive management of these infants.

Hydrocephalus

Our team performs a thorough evaluation to determine the most appropriate treatment for hydrocephalus. The goal of treatment is to reduce the pressure in the child's head and to properly drain the cerebrospinal fluid. If surgery is needed, our team has vast experience with shunting. Because of the volume of patients we treat with this condition, our team is adept at monitoring for and recognizing complications from shunting and provides the prompt medical interventions necessary. Hypoxic-Ischemic Encephalopathy

The CHOP Newborn/Infant Intensive Care Unit offers a Therapeutic Hypothermia Program for infants with hypoxic-ischemic encephalopathy. This therapy, which involves whole body cooling, is neuroprotective after certain brain injuries in infants. The therapy is indicated for term or near-term infants with a moderate or severe perinatal or early postnatal hypoxic-ischemic event. Our team is currently engaged in an Optimizing Cooling trial to examine whether cooling for a longer time period and/or to a lower temperature improves the chance of survival and neurodevelopmental outcomes at 18–22 months corrected age.



#### Minimally Invasive Surgery Program

The Minimally Invasive Surgery Program at CHOP allows infants and children to have advanced surgical treatment without the pain and scarring of traditional surgical approaches. CHOP surgeons offer minimally invasive approaches to a wide range of thoracic and abdominal diseases. Advanced techniques, custom equipment and specially-trained staff allow adaptation of these methods to the neonate, yielding procedures that are safer, faster and gentler on babies.

The program is led by Thane Blinman, M.D., who

has a keen interest in advancing minimally invasive surgery, particularly in neonates. During his time at CHOP, Dr. Blinman has pioneered the use of robotic surgery in particularly vulnerable populations of children, such as those with conditions like congenital diaphragmatic hernia, congenital cystic adenomatoid malformation and Hirschsprung's disease.

CHOP surgeons have pioneered techniques offered nowhere else. These approaches have broadened surgical options, shortened stays and reduced costs while improving technical results in gastroesophageal reflux, diaphragmatic hernia, choledochal cyst, cystic adenomatoid malformation, malrotation and many other surgical diseases of infants.

#### EDUCATION, OUTREACH AND RESEARCH

#### **Fellowship Education**

The Children's Hospital of Philadelphia takes seriously its responsibility to train the next generation of neonatologists. CHOP is the University of Pennsylvania's pediatric teaching hospital, and the three-year Neonatal-Perinatal Fellowship Program is designed to train the pediatrician for a career in academic neonatal-perinatal medicine.

The Neonatology Fellowship education program includes:

- Comprehensive training in the clinical care of sick neonates in the inborn and out-born setting
- Fellows and residents working alongside pediatric house physicians and neonatal nurse practitioners in the N/IICU, under the supervision of attending neonatologists
- A structured curriculum for continuous education in perinatal and neonatal physiology, biostatistics and epidemiology, and participation in long-term follow-up of infants discharged from the N/IICU
- Weekly participation in both clinical and research conferences (presentations mostly by fellows)
- Hands-on learning through neonatal simulation for ventilator management, delivery room management, ECMO, surgery and codes
- Structured research experience in basic biological sciences, clinical trials, epidemiology and health services research, or education, depending on the interests and career goals of the trainee

#### Neonatal Outreach Program

The Neonatal Outreach Program, established in 2003, serves the needs of all referring physicians including and beyond the immediate Delaware Valley. Our referrals come from neonatologists, pediatricians and physicians in local emergency rooms.

The program's primary goal is to provide a direct link to Neonatology at CHOP and ensure effective communication regarding subspecialty referrals, ongoing inpatient evaluation and care, transport, referrals, and discharge information.

The team recognizes and highly values the expertise offered by referring physicians and encourages their participation in weekly clinical conferences and clinical consensus meetings. The team also coordinates clinical education opportunities (physician grand rounds or nursing in-services) for staff at referring institutions.

For additional program information, patient follow-up information, educational offerings and inquiries:

- Patti O'Connor, R.N., nurse coordinator, Neonatal Outreach Program, oconnorp@email.chop.edu, 215-590-2616
- Janet Lioy, M.D., Medical Director, Neonatal Outreach Program, lioy@email.chop.edu

#### Neonatology Research

The Children's Hospital of Philadelphia is a leader in the advancement of basic and clinical research. We have one of the nation's largest pediatric research programs, spanning virtually every area of pediatric medicine. The knowledge that is gained from our studies has led and will continue to lead to improved healthcare for children worldwide.

Our clinical and basic research activities are conducted through The Children's Hospital of Philadelphia Research Institute. The Institute oversees the work of more than 150 investigators and their staffs who are pursuing hundreds of active research projects at any given time. Children's Hospital ranks among the top two pediatric hospitals nationwide in funding from the National Institutes of Health.

Current areas of research in neonatology-related topics include:

Pulmonary

- Fetal lung development
- Lung antioxidant defenses
- Lung disease in premature infants
- Congenital diaphragmatic hernia and complex lung lesions
- Role of inflammation in lung disease
- Pulmonary function testing in the neonate
- Hormone regulation of fetal lung development
- Use of inhaled nitric oxide in premature infants
- Hormone regulation of fetal lung development
- The role and regulation of heme oxygenase in lung antioxidant defenses

Neurology

- Effect of inflammation and oxidative stress on the neonatal brain
- Neuroimaging and neurodevelopmental outcomes
- Biomarkers and neonatal brain injury
- Management of myelomeningocele (the most severe form of spina bifida)
- Maternal drug use and neonatal neurodevelopmental outcomes

#### Genetics

- Oxidative stress mediated gene regulation
- Fetal origins of adult disease
- Surfactant protein processing and physiology
- Biological chemistry and molecular mechanisms of action in nitric oxide
- Intrauterine growth retardation and insulin resistance
- Effect of maternal obesity on the fetus
- Mitochondrial biology
- Biomarkers of neonatal sepsis
- Serum biomarkers in necrotizing enterocolitis
- Neonatal pharmacokinetics
- Cell motility and proliferation; process of inflammation and fibrosis following tissue injury
- Surfactant protein processing and physiology
- Surfactant clinical trials booster prophylaxis and rescue therapy

#### Cardiac

Development of the conotruncal region of the heart

#### General

- Neonatal health services research
- Impact of neonatal outreach on referral patterns
- Multicenter trials to assess safety and efficacy of neonatal therapies
- Simulation strategies for neonatal education
- Community satisfaction of neonatal Level 4 care

#### Current clinical studies by investigators in the Division of Neonatology include:

- A randomized controlled trial of the effect of hydrocortisone on survival without bronchopulmonary dysplasia and on neurodevelopmental outcomes at 22–26 months of age in infants intubated less than 30 weeks gestational age.
- A multicenter randomized trial of laparotomy vs. drainage as the initial surgical therapy for extremely low birth weight infants with necrotizing enterocolitis or isolated intestinal perforation: outcomes at 18–22 months adjusted age.
- Strategies for optimizing cooling strategies at less than 6 hours of age for neonatal hypoxic-ischemic encephalopathy.
- A study of the neurodevelopmental effects of donor human milk vs. preterm formula in extremely low birth weight infants.
- A biologic sample study for the validation of biomarkers of progressive necrotizing enterocolitis and sepsis.
- A study of the impact of bacterial polymerase chain reaction and cerebrospinal fluid cytokine levels on the diagnosis of bacterial meningitis in infants.

#### **CHOP NEWBORN CARE LOCATIONS**

Families in every part of the greater Philadelphia region have access to excellent neonatal services through CHOP Newborn Care. CHOP's nationally-renowned Division of Neonatology provides comprehensive care in the intensive care nurseries at these hospitals:

Hospital of the University of Pennsylvania 3400 Spruce St., 8 Ravdin Building Philadelphia, PA 19104 Main: 215-662-4000 NICU: 215-662-3884

The intensive care nursery (ICN) at the Hospital of the University of Pennsylvania is a 36-bed Level III unit with roughly 900 admissions per year of critically ill neonates from all over the region. The ICN team has expertise in the care of high-risk premature babies and resuscitation of infants with complex congenital malformations including congenital heart disease, congenital diaphragmatic hernia, congenital cystic adenomatoid malformation, abdominal wall defects and hydrops fetalis.

The ICN is staffed by neonatologists, fellows, pediatric residents, nurse practitioners and physician assistants. Infants in the ICN may receive care from subspecialists including those from Cardiology, Cardiothoracic Surgery, Pulmonology, Hematology, Genetics/Metabolism, Neurosurgery and Infectious Diseases. Ophthalmologists perform routine weekly eye examinations and laser therapy as needed for retinopathy of prematurity. Cardiothoracic surgeons are available to perform PDA ligations in the ICN.

The ICN has a therapeutic hypothermia program and has just started a donor breast milk program for infant nutrition. It is an active member of the Vermont Oxford Network, and nurses in the ICN and throughout the hospital are Magnet certified.



Pennsylvania Hospital 8th and Spruce Streets Philadelphia, PA 19107 Main: 215-829-3000 NICU: 215-829-5069

Pennsylvania Hospital, the nation's first hospital, was founded in 1751 by Benjamin Franklin and Dr. Thomas Bond. Today, the hospital is known for services including obstetrics, high-risk maternal and fetal services, and neonatology. The hospital has more than 4,000 births annually. The 40-bed full-service Level III NICU is designed for the care of extremely low birth weight premature infants up to full-term infants with respiratory failure, sepsis, genetic syndromes and other neonatal conditions. The unit provides conventional ventilation, high-frequency oscillation, jet ventilation and nitric oxide care for milder forms of respiratory failure.

Surgical services include laser surgery for ROP and PDA ligation. Both apnea diagnostic and neonatal follow-up programs are also on site to provide comprehensive care after discharge. Neonatal transport services from the CHOP Transport Team are available for outside referrals.

The team includes 24-hour neonatologists, neonatal nurse practitioners, physician assistants, pediatric residents and respiratory therapists. Pediatric and pediatric surgical subspecialists from CHOP are also available for consultation in the NICU. Social workers, occupational and physical therapy teams, speech and feeding specialists, developmental specialists, and lactation consultants work with both babies and families.

Chester County Hospital 701 East Marshall Street West Chester, PA 19380 Main: 610-431-5000 NICU: 610-431-5394

CHOP Newborn Care at Chester County Hospital features a 12-bed Level III Neonatal Intensive Care Unit which provides comprehensive medical care for extremely premature infants weighing less than a pound to full-term infants with multiple complex medical issues.

Perinatology services are available around the clock, with Level II ultrasounds, fetal echocardiograms, chorionic villus sampling (CVS) and genetic counseling. A neonatologist or neonatal nurse practitioner is on site 24/7 for NICU patients and for consultation for any newborn infant. CHOP subspecialty care is readily accessible to assist the neonatal staff.

The unit offers parents a separate breastfeeding room as well as a parent participation room that is used to help families transition from the ICU to their home environment. The Chester County NICU participates in national quality collaborative projects and is in the top rankings for many Vermont Oxford Network database quality measures.

Doylestown Hospital 595 West State Street Doylestown, PA 18901 Main: 215-345-2200 Birthing Center: 215-345-2229 Special Care Nursery: 215-345-2960 Neonatology Office: 215-345-2054

CHOP Newborn Care at Doylestown Hospital provides Level II care for premature and ill babies. The unit's team includes board-certified neonatologists, specially trained pediatricians, nurses and lactation consultants. The hospital also has pediatric cardiologists, orthopedists, neurologists, ENTs, geneticists and ophthalmologists on staff to provide consultations in the unit.

The hospital offers perinatal care — with delivery of 1,200 to 1,400 babies each year — with a strong emphasis on evidence-based medicine, and has received the highest health grade scores in Bucks County. Doylestown Hospital has a strong commitment to nurturing babies and is one of very few hospitals in the area to offer human donor milk.

A new state-of-the-art intensive care nursery with eight beds (double from current beds) is underway and will enable the hospital to care for a greater number of babies in the near future.

Grand View Hospital 700 Lawn Avenue Sellersville, PA 18960 Main: 215-453-4000 Special Care Nursery: 215-453-4907

CHOP Newborn Care at Grand View Hospital includes a newly-built Level II NICU with six beds. The unit manages 1,600 deliveries a year, and that number is steadily on the rise. Available services include maternalfetal medicine, perinatal testing, lactation services, "nesting rooms," 24-hour in-house coverage by CHOP's board-certified neonatologists and hospitalists, and consultation from CHOP radiologists and cardiologists, who provide ECHO services.

Holy Redeemer Hospital 1648 Huntington Pike Meadowbrook, PA 19046 Main: 215-947-3000 Special Care Nursery: 215-938-2903

CHOP Newborn Care at Holy Redeemer Hospital features a 19-bed Level III neonatal intensive care unit staffed by neonatologists and skilled critical care nurses, with on-site cardiology, ophthalmology and gastroenterology consults as needed. The hospital has seven maternity triage beds and six additional postpartum beds. It delivers about 3,000 newborns and cares for about 250 babies in its NICU each year.

In-house neonatologists and neonatal nurse practitioners provide 24-hour coverage with access to all CHOP subspecialists for consultation. Transport to Holy Redeemer for convalescent pre-discharge care is available through the CHOP Transport Team.

An active apnea program coordinates care between the infant's primary provider and the neonatal team after discharge. A high-risk developmental follow-up clinic evaluates and refers NICU graduates for focused, continued services after discharge.

The Holy Redeemer NICU participates in the Vermont Oxford Network for benchmarking and quality improvement.

Phoenixville Hospital 140 Nutt Road Phoenixville, PA 19460 Main: 610-983-1000 Special Care Nursery: 610-983-1785

CHOP Newborn Care at Phoenixville Hospital features a four-bed Level II NICU that has cared for more than 1,000 babies since opening 10 years ago. The unit features a newly expanded Women's Health Pavilion with large, private postpartum rooms and state-of-the-art technology. Phoenixville's experienced NICU team includes board-certified CHOP neonatologists and nurse practitioners on-site 24 hours a day, seven days a week. The hospital offers outpatient consultation by neonatologists for families with high-risk pregnancies. Specialists available on site for consult include audiologists, ophthalmologists, orthopedic surgeons and pediatric cardiologists who provide fetal echocardiograms. Prenatal education classes include birth preparation, infant CPR and sibling preparation, and support services include a NICU social worker, postpartum adjustment support group and lactation services.

University Medical Center at Princeton-Plainsboro 1 Plainsboro Road Plainsboro, NJ 08536 Main: 609-853-7000 Special Care Nursery: 609-853-7650

The CHOP Newborn Care Level II Special Care Nursery at the University Medical Center (UMC) at Princeton-Plainsboro is staffed 24/7 by board-certified neonatologists and specially trained neonatal nurses. The hospital currently welcomes approximately 2,000 new births each year and cares for 200 infants annually. This includes preterm as well as term infants requiring special care, including infections, transfusions, ventilator support and growth management.

The new 14-bed intensive care nursery features individual patient rooms to enhance patient privacy and familycentered care. UMCP has a strong breastfeeding program and is on the path toward UNICEF/WHO Baby-Friendly designation.

CHOP's perinatologists are affiliated with Penn Medicine and can provide care and consultative service to high-risk obstetrical patients, including chorionic villus sampling, amniocentesis and genetic counseling, as well as management of multiple gestations. Neonatal consultations are available from CHOP cardiologists and ophthalmologists. Home apnea monitoring follow-up is provided through our infant apnea program.

CHOP at Virtua Voorhees 100 Bowman Drive Voorhees, NJ 08043 Main: 856-247-3000 NICU: 856-247-3831

CHOP Newborn Care at Virtua Voorhees is a state-designated Regional Perinatal Center providing the highest level of care for mothers and babies in South Jersey. Close to 5,600 babies are delivered each year in the Voorhees campus, of which more than 800 are admitted to the NICU. Board-certified maternal-fetal medicine specialists provide comprehensive services on-site for women with high-risk pregnancies.

The 46-bed Level III NICU has private rooms equipped with the latest technology, a family seating area, and large windows that provide natural lighting. The NICU is staffed around the clock by board-certified neonatologists and neonatal nurse practitioners, trained neonatal nurses, and respiratory therapists who provide state-of-the-art neonatal intensive care for low birth weight, preterm and term sick newborns with a wide range of medical conditions. A team consisting of dieticians, lactation consultants, pharmacists, social workers, physical therapists and developmental specialists provides ancillary support to further enhance the care of these babies.

Treatment modalities and procedures include conventional ventilation, high frequency ventilation, CPAP, high flow nasal cannula, inhaled nitric oxide therapy, PICC lines, exchange transfusions and bedside PDA ligations. The High-Risk Infant Follow-up team sees babies at risk for growth and neurodevelopmental issues up to age 2 and coordinates care and intervention when required. Close to 550 babies are seen in the clinic each year.

Virtua Memorial 175 Madison Avenue Mount Holly, NJ 08060 Main: 609-267-0700 NICU: 609-261-7053

CHOP Newborn Care at Virtua Memorial is a 12-bed Level II neonatal unit within the only full-service hospital with maternity care in Burlington County. The unit delivers close to 2,900 babies each year. Women with high-risk pregnancies are seen in the Antenatal Testing Unit and followed by board-certified maternal-fetal medicine specialists.

The newly renovated Special Care Nursery (SCN) at Virtua Memorial provides intensive and intermediate care to around 350 babies each year. Low birth weight, premature and term infants with complications such as respiratory distress, sepsis, jaundice, hypoglycemia, drug withdrawal, poor feeding, acyanotic heart disease and other birth defects are cared for by a team of board-certified neonatologists, neonatal nurse practitioners and trained nurses.

The SCN is equipped with state-of-the-art warmers, isolettes and electronic monitors. Babies who require short-term mechanical ventilation, CPAP or oxygen therapy by nasal cannula are managed in the SCN under close supervision of the clinical team and dedicated respiratory therapists.

The SCN staff members are strong proponents of family-centered care. Constant effort is made to create a warm, nurturing environment in which to provide developmental care for babies. Families are educated, supported and encouraged to get involved in their babies' care. A Ronald McDonald Family Room provides families a soothing place for relaxation and refreshment. Visitation is 24 hours a day, and siblings 5 years and older are allowed to visit.

#### **CHOP REFERRAL NUMBERS**

Patient Scheduling: CHOP Access Center: 1-800-TRY-CHOP (1-800-879-2467)

**Critical Care and Emergency Services:** Cardiac Intensive Care Unit: 215-590-2644 Emergency Transport Program: 215-590-2160 or 1-800-590-2160 Newborn/Infant Intensive Care Unit: 215-590-3083 Pediatric Intensive Care Unit: 215-590-2651

#### **Diagnostic Services:**

Clinical Laboratory Results: 215-590-2277 Radiology Results: 215-590-2584

#### **Department and Division Phone Numbers:**

Cardiology: 1-877-77HEART (1-877-774-3278) Dermatology: 215-590-2169 Endocrinology: 215-590-3174 Gastroenterology, Hepatology and Nutrition: 215-590-3630 General, Thoracic and Fetal Surgery: 215-590-2730 Hematology: 215-590-4179 Infectious Diseases: 215-590-2549 Metabolic Disease: 215-590-3376 Neurology: 215-590-1719 Neurosurgery: 215-590-2780 Ophthalmology: 215-590-2791 Otolaryngology: 215-590-3440 Plastic and Reconstructive Surgery: 215-590-2208 Pulmonary Medicine: 215-590-3749 Radiology: 215-590-7000 Urology: 215-590-2754

#### Multidisciplinary Center Phone Numbers:

Center for Thoracic Insufficiency Syndrome: 215-590-1527 Congenital Hyperinsulinism (HI) Center: 215-590-7682 Pediatric Feeding and Swallowing Center: 215-590-7500 Special Delivery Unit: 215-590-6900 Spina Bifida Program: 215-590-1760

#### **Specialty Care Center Numbers:**

#### Pennsylvania

**Specialty Care Center Abington** phone: 215-885-2790 fax: 215-881-7140

Specialty Care Center Bucks County phone: 215-997-5730 fax: 215-997-5731

Ambulatory Surgery Center Bucks County phone: 215-997-0133 fax: 215-997-3604 Specialty Care Center Chadds Ford phone: 610-459-7871 fax: 267-426-1289

**Specialty Care Center Exton** phone: 610-594-9008 fax: 610-594-1907

Ambulatory Surgery Center Exton phone: 610-594-9050 fax: 610-594-1907

Specialty Care Center King of Prussia phone: 610-337-3232 fax: 610-337-0325

Sports Medicine and Performance Center King of Prussia phone: 610-768-9470 fax: 215-590-5480

Specialty Care Center Springfield phone: 610-328-1600 fax: 610-328-1693

#### New Jersey:

Specialty Care Center Atlantic County phone: 609-677-7895 fax: 609-677-7835

Specialty Care Center Princeton phone: 609-520-1717 fax: 609-520-9333

Saint Peter's University Hospital Cardiology Specialty Care Center phone: 732-846-2855 fax: 732-745-4680

Specialty Care Center – Voorhees phone: 856-435-1300 fax: 856-435-0091

Cardiology – Voorhees phone: 856-783-0287 fax: 856-783-0657

Gastroenterology – Voorhees phone: 856-435-0086 fax: 856-435-5072

Hematology/Oncology – Voorhees phone: 856-435-7502 fax: 856-435-6936

Ambulatory Surgery Center – Voorhees phone: 856-782-8750 fax: 215-590-2559

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## The Children's Hospital of Philadelphia®

### Hope lives here.

Founded in 1855, The Children's Hospital of Philadelphia is the birthplace of pediatric medicine in America. Throughout its history, a passionate spirit of innovation has driven this renowned institution to pursue scientific discovery, establish the highest standards of patient care, train future leaders in pediatrics, and advocate for children's health. A haven of hope for children and families worldwide, CHOP is a nonprofit charitable organization that relies on the generous support of its donors to continue to set the global standard for pediatric care.

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