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**Feeding disorders are an enduring problem we are addressing using multidisciplinary teams.**

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# Old Problems: New Solutions

**H**ave you ever heard someone say, “It’s always like that”, or “We’ve always done it that way”? Comments such as these are made when we are stuck in a rut and need to change our focus and try a new solution to an issue that continues to be problematic for us.

At Nationwide Children’s, our Quality Improvement model is to use the PDSA cycle: Plan, Do, Study, Act. The methodology allows for many small tests of change to be applied before moving forward across the system with an entire change. The PDSA cycle can start with one patient at one visit or encounter. Data is then analyzed from one test to see if the predicted result was achieved. If so, during the Act phase, the change is dropped or tested on more processes to see if the same results occur. The plan is then modified or implemented. The cycle then repeats itself with a new plan until results for the process of care or procedure can be spread across a system or put into policy.

Our work to drive to zero preventable harm has brought many new solutions to old problems. In some cases, our PDSA cycles have revealed problems we were not aware existed, as in the case of pressure injuries. The use of the turning clock, which was first used in the Pediatric Intensive Care Unit, has been implemented in additional areas. The use of skin rounds for injury detection and teaching, a practice which began in Pediatric Intensive Care Unit and Cardio Thoracic Intensive Care Unit, has been implemented in all units with high risk patients.

The same methodology for studying these issues can also be applied to our personal lives, processes and patient populations for improving their care. The first step is to move past “We’ve always done it that way” and be willing to start a plan to find a new solution. Enjoy discovering new solutions as you read about changes to care in this issue of “Everything Matters: In Patient Care”.



# Feeding Enhancement Program Helps Premature Infant Reach Feeding Milestones

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## Background

Despite advances in technology, premature birth continues to impose unexpected misery and hardship on families. Prematurity also seriously challenges the NICU team to devise methods to achieve better outcomes and lower the economic burden on the health care system. The acquisition of oral feeding skills may not be the major concern for an anxious parent of a premature infant in the NICU, but it has been shown to impact parent/infant bonding which in turn affects the infant's neurodevelopmental outcome. In addition to decreasing parent satisfaction, delay in oral feeding acquisition has been identified as one of the major causes for increased length of stay (LOS) in the hospital as well as subsequent economic burden for the neonatal population as a whole.

The sources for *neonatal feeding disorders* can be variable and provider-dependent. One major expectation of every parent of a baby born prematurely is to take the infant home on full oral feeds as soon as possible. This expectation can only be realized if the integrated functions of the premature gut, brain and airway interact optimally, and the clinical care providers minimize variability in their practices to enhance infant feeding capabilities.

At Nationwide Children's over the last decade, cutting edge research in the Innovative Feeding Disorders

Program has resulted in better understanding of the integrative physiology and pathophysiology of premature gut, brain and airway interactions. The results of these studies further advanced the field in the development of innovative individualized feeding strategies targeting the dysfunctional mechanisms within the infant. Having achieved success in the modification of feeding skills and preventing placement of gastrostomy tubes, the Innovative Feeding Disorders Program was challenged to simplify and further develop uniform feeding approaches to enhance feeding skills by 38 weeks postmenstrual age (PMA) primarily, and to reduce length of hospital stay secondarily. This goal resulted in the development of the Feeding Enhancement Program (FEP), a multidisciplinary program charged with the mission of achieving feeding success by 38 weeks PMA. The intention of the FEP was officially recognized to provide progressive, peer reviewed research knowledge to providers at the bedside as well as disseminating new data pertinent to infant feeding and aero-digestive safety.

## The Approach

The major approaches within the Feeding Enhancement Program include a) optimizing the process of providing nutrition from admission to discharge, b) targeting achievement of feeding milestones in a timely manner, c) education of the feeding providers, e.g. MDs, NNPs, RNs, PCAs, occupational therapists, dieticians, lactation



specialists, pharmacists and parents, d) monitoring feeding compliance, and e) recommending innovative approaches at feeding rounds twice per week.

The FEP program enlisted multidisciplinary participation and included feeding champions across all neonatal disciplines: physicians, nurse practitioners, bedside nurses, occupational therapists, nutritionists, lactation specialists, pharmacists and, most importantly, parents. A survey was first conducted to identify areas of variability in neonatal feeding practices. Pre-implementation survey of providers showed an overwhelming need for: 1) nursing and parent education, 2) individualized and simplified feeding care plans for eligible infants, and 3) timely diagnosis. Using these results, guidelines were developed to target acquisition of feeding milestones by specific PMA. The work was divided into areas of concentration; focus groups were formed to establish standardization of feeding practices from evidence based approach.

To accomplish the objectives of the feeding enhancement program, six multidisciplinary focus groups were established, comprised of volunteers from the feeding champions.

1. The *Rounds Readiness Focus Group* was created with the goal of developing an efficient process to identify new patients for rounds, create and develop standardized rounding tools to evaluate risk factors and patient progress, and improve interdisciplinary involvement in weekly rounds.
2. The *Tube Feeding Initiation and Maintenance Group* emphasized standardizing the introduction of trophic feeds and enteral feeding progression as well as regulating feeding tube size.
3. The goal of modifying and simplifying the existing Cue-Based Feeding protocol in an effort to attain full oral feeds earlier was undertaken by the *Oral Feeding Initiation and Maintenance Group*.
4. The *Drug Utilization Group* arose with the aim of developing methods to monitor and evaluate side effects and complications associated with medications such as proton pump inhibitors, H2 receptor antagonists and antibiotics usage. This group also dedicated part of their focus on examining TPN usage within the nurseries.
5. The responsibility of addressing barriers for staff and families related to achieving feeding milestones was assumed by the *Provider/Parent Education Group*.
6. The *Order Sets Focus Group* was formed to ensure timely reminders for feeding orders and best practices alerts when prompted.

The work of the Feeding Enhancement Program was first implemented by establishing feeding rounds. Feeding rounds are centered on objective evidence, literature review, education, and research from within Nationwide Children's institution and others. Evidence-based individualized feeding plans suitable to each patient during multidisciplinary feeding rounds are then developed. Compliance to the feeding plan is monitored weekly by using rounding tools that track milestone progress and recommendations towards the feeding plan of care.



The patient is presented to the members of the FEP by the bedside nurse using a standard format that includes a history, evaluation of feeding risk factors and current feeding status. An individualized feeding plan is then devised and communicated to the team. Parental concerns and questions are addressed. Teaching is provided to both parents and caregivers from current evidence. Weekly progress and recommendations are noted on the tools each week.

### The Future

Having launched the program successfully, the future goals are to sustain the enhancement of acquisition of feeding milestones, decrease the variability of feeding practices, continuous monitoring of feeding milestones, and increase knowledge base among feeding providers. By encouraging and including parent involvement in the feeding plan of their infant and empowering them

in the decision making process, attachment and bonding can be enhanced.

### Summary

The acquisition of feeding skills in the premature infant is not usually of foremost concern for an anxious parent or the frequently changing provider. Delays in acquisition of enteral and oral feeding milestones are some of the important reasons for prolonged length of hospital stay and related co-morbidities. In this initiative, the approach was to optimize the process of providing feedings in a timely and targeted manner as well as to provide education to the multi-disciplinary feeding providers. It is anticipated that this approach will minimize variability among feeding providers, increase confidence to analyze feeding related symptoms, and continue to provide guidance to achieve targeted feeding milestones.

**By encouraging and including parent involvement in the feeding plan of their infant and empowering them in the decision-making process, attachment and bonding can be enhanced.**



# Should Non-Immunized Children Be Excluded From A Pediatric Practice?

Pedro Weisleder, MD, PhD, Co-Chair of Nationwide Children's Hospital Integrated Ethics Committee

Vaccines are among the most effective prevention tools available to clinicians. High immunization coverage has resulted in drastic declines in vaccine-preventable diseases. And for those who cannot be immunized, “herd effect” - the phenomenon by which a disease is squeezed out of a community due to a lack of hosts capable of transmitting it - offers a potentially lifesaving option. Unfortunately, the low incidence of vaccine preventable diseases has led some to wrongly believe the conditions have been eradicated - we have become victims of our own success.

The number of parents who refuse to vaccinate their children by seeking a personal-belief exemption (PBE) has been steadily increasing. Between 1991 and 2004 the number of PBE to immunizations rose from 0.99% to 2.54%. Using 2010 data from The Federal Interagency Forum on Child and Family Statistics, it is reasonable to conclude that, based on parental PBE, almost 2 million American children are unvaccinated today. That number is much higher in certain metropolitan areas such as Seattle and San Diego.

Pediatricians have the privilege and responsibility to care for a vulnerable population. We are entrusted and expected to work in concert with parents and act in the best interest of our patients. Our responsibility, however, is not only to the child in the examining room; it is also to those in the waiting room. Many of the vaccine-preventable illnesses cause significant morbidity in children with no underlying medical problems. They have the potential to be devastating or fatal in children who do. It is not uncommon for pediatricians to provide routine care to patients on long-term daily corticosteroids or other immunomodulators for juvenile idiopathic arthritis,

Crohn's disease, cancer, and reactive airway disease. An infection with varicella, Haemophilus influenzae type B, measles, or certain strains of Streptococcus pneumoniae - all vaccine-preventable illnesses - could be fatal if acquired by such patients.

As a consequence, some clinicians have discontinued or have considered severing their provider relationship with families that refuse vaccines. For those pediatricians it is a matter of societal responsibility and unwillingness to practice sub-standard medicine. The American Academy of Pediatrics (AAP) does not challenge the nobility behind those principles. It does, however, question the wisdom of discharging patients from a practice solely because of parental refusal to immunization.

In an effort to assist practitioners, the AAP has developed recommendations and practical tools to foster communication with the parents of unvaccinated children. Specifically, the AAP recommends:

1. Share honestly what is known and what is not known about the risks and benefits of the vaccine in question;
2. Address vaccine refusal by respectfully listening to parental concerns, explaining the risk of nonimmunization, and discussing the specific vaccines that are of most concern to parents;
3. Document details of the conversations and have the parent sign a vaccine refusal form (for an example see <http://practice.aap.org/popup.aspx?aID=2685&language=>); keep the form in the patient's medical record;
4. Flag the chart to be reminded to revisit the immunization discussion as well as to alert the provider about missed immunizations when considering the evaluation of other illness.

*If you are interested in learning more about the services of the Nationwide Children's Ethics Committee, contact Pedro Weisleder at [Pedro.Weisleder@NationwideChildrens.org](mailto:Pedro.Weisleder@NationwideChildrens.org).*



# Neurobiological Changes in Youth with PTSD

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Over 25 percent of children will experience a significant traumatic event before reaching adulthood. Posttraumatic Stress Disorder (PTSD) is an anxiety disorder that is characterized by exposure to a traumatic event associated with intense fear and helplessness. This experience results in changes to the neurochemical system that can lead to symptoms including intrusive recollection, avoidance and numbing, as well as hyperarousal for more than one month and causes significant distress or functional impairment.

Given the prevalence of childhood trauma, it is important to consider its effects on brain development. Early in childhood, the neurons and synapses are consistently growing and being pruned. This process is thought to be completed around age 4 years. Myelination and overall volume growth in the prefrontal cortex, limbic area, including the amygdala and hippocampus, and subcortical gray matter continues into the third decade of life.

The response to trauma appears to be mediated by the amygdala, locus ceruleus and the hypothalamic-pituitary-adrenal axis (HPA axis). The amygdala is key in assessing the biological and emotional perception of threat. Alterations in catecholamine secretion have been implicated in the development of PTSD in children and adolescents. High amounts of stress or trauma can increase the activity in the locus ceruleus, the major norepinephrine nucleus of the brain, and increase noradrenergic activity in the amygdala. These catecholamines, including norepinephrine, epinephrine and dopamine, have been implicated in arousal, anxiety, frontal lobe activation, affective regulation, reward and

dependence circuitry, memory, thinking and perceiving. These higher levels of catecholamines can negatively affect important areas, especially the prefrontal circuits. Under stress, there can also be a dysregulation in the HPA axis leading to increased cortisol. Elevated catecholamines and cortisol may lead to mechanisms of accelerated loss of neurons, delays in myelination, and inhibited neurogenesis. In 2004, Cohen suggests that trauma induced amygdalar over-reactivity and pre-frontal cortex under-reactivity may be responsible for the re-experiencing symptoms and hyperarousal associated with PTSD.

If there is repeated exposure to fearful situations, there can be an over-sensitization where even minor stimuli can provoke an inappropriately high amygdalar response. As a result, traumatized youth may have an inappropriate response to a minor, non-trauma-related trigger and lead to a full “fight or flight” response. There have been repeated studies that demonstrate hyper-secretion of morning cortisol in sexually abused girls and high levels of free and salivary cortisol as well as urinary dopamine and norepinephrine in maltreated youth with PTSD. Imaging studies showed children with PTSD had smaller intracranial, cerebral, right temporal lobe, and corpus callosum volumes. These studies biologically confirm the physiological changes in response to trauma.

Psychosocially, children with a history of exposure to violence have demonstrated decreased empathy and prosocial behaviors as well as increased aggression towards self and others, that ultimately undermine the development of a social network. There is a disruption in the normal development of trust, the emergence of autonomy, and emotional self-regulation. Ultimately, the



child demonstrates a poor sense of self, lack of affective modulation and impulse control, and disturbances of body image. Huth-Bocks’ study of children who witnessed domestic violence during the last year demonstrated poorer verbal abilities than non-witnessed domestic violence. Testing in these children has shown memory deficits further interfering with academic and social achievement. These children grow up with an increased risk for substance use, suicidal ideation, health care use, and criminal acts.

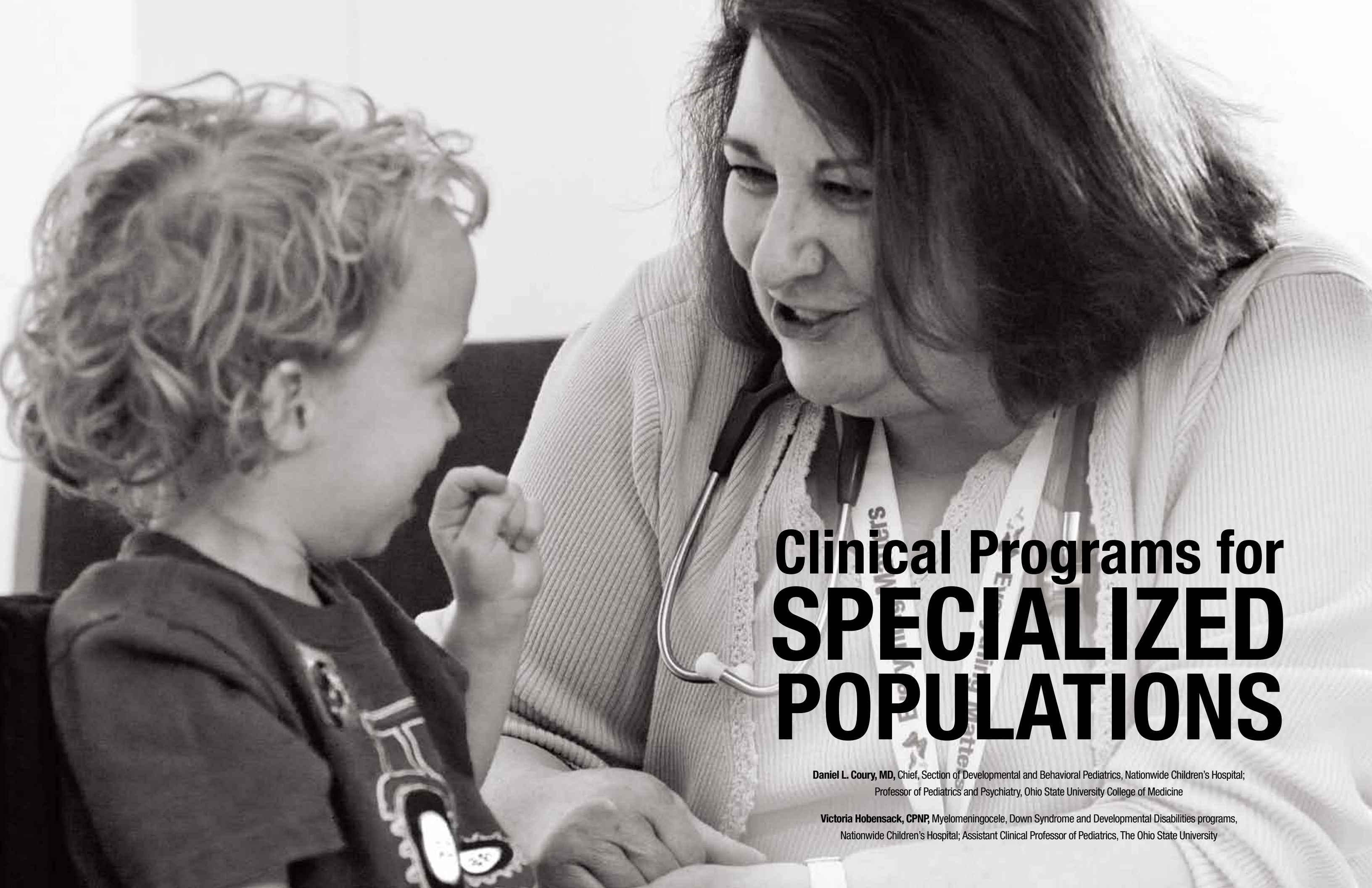
Although the research of psychopharmacologic treatment of PTSD symptoms in youth is limited, it stands to reason that using our knowledge of the neurobiological and psychosocial changes can inform future medication management. Children with PTSD may benefit from treatment that targets decreasing adrenergic responses, decreasing dopaminergic activity, and increasing neuronal availability of serotonin. Therefore, the medications most often prescribed include selective serotonin reuptake inhibitors (SSRIs), tricyclic antidepressants (TCAs), serotonin-norepinephrine reuptake inhibitors (SNRIs), alpha-2-receptor agonists, cyproheptadine, and atypical antipsychotics. SSRIs can increase the level of serotonin in the brain which helps to improve mood, emotional state and sleep/wake cycle.

They remain among the most promising agents for the treatment of PTSD and deserve additional study in larger randomized controlled trials. Similarly, adrenergic agents are thought to play a role in decreasing the physical experience of trauma related symptoms such as hyperarousal and nightmares, and the field would likely benefit from further evaluation.

Despite some understanding of the neurophysiological response to trauma, there is limited evidence behind other treatments for PTSD. There are currently no available studies of the use of medication to prevent the development of PTSD in traumatized children. At this time, there is a fairly well-established body of evidence documenting the success of psychotherapeutic interventions such as Trauma Focused Cognitive Behavioral Therapy for PTSD, that it is current practice to consider psychopharmacologic treatments as an adjunctive measure in the management of pediatric PTSD. Further pharmacologic and therapeutic treatments may be discovered with a deeper understanding of the neurobiological changes associated with trauma.

*Reference materials are available upon request by calling (614) 722-5962.*





# Clinical Programs for **SPECIALIZED POPULATIONS**

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Nationwide Children's will have over one million patient encounters in 2012 through our inpatient wards and our numerous outpatient services, including the emergency department, primary care network and specialty clinics. When a medical center this large treats so many children and adolescents from such a large referral area, cases of rare disorders begin to be seen more frequently than in other medical centers. The subtle differences in diagnosing and treating these less common conditions become more apparent when the same group of professionals encounters them, and awareness of the special needs of such populations leads to better care for each patient with the condition. This has led to several specialized clinical programs over the years.

### Myelomeningocele Program

Myelomeningocele, also referred to as spina bifida, is a condition caused by a failure of neural tube closure during pregnancy. This leads to a defect in the spine which may present with a large opening and exposed spinal cord and, as a result, a variety of neurologic problems. The failure of normal spinal cord development can lead to problems with use of the lower extremities, ranging from weakness in the hips, legs and feet to complete paralysis of the legs. This neurologic defect also affects sensation in these areas. Abnormal nervous system control of this area of the body can also cause a loss of bladder and bowel control; these problems can lead to recurrent urinary infections, urinary and bowel incontinence and constipation. The defect in the development of the spine and central nervous system also leads to a high rate of hydrocephalus and frequently requires a shunt to remove the spinal fluid.

The Myelomeningocele Program at Nationwide Children's has a team led by Dr. Karen Ratliff-Schaub, a developmental pediatrician, along with members representing neurosurgery, orthopedics, urology, physiatry, neuropsychology and genetics as well as representatives from clinical therapies such as occupational therapy (OT) and physical therapy (PT). The team also utilizes a social worker and three case coordinators. The Myelomeningocele Program has been in operation for over forty years. Recently,

under the leadership of Vickie Hobensack, RN, CPNP, Dr. Ratliff-Schaub and Judy Griffey, RN, MS, the Myelomeningocele Program at Nationwide Children's was selected by the Centers for Disease Control and Prevention to become one of 17 spina bifida programs in the country participating in the National Spina Bifida Registry Demonstration Project, whose purpose is to track long-term outcomes for children and adults with spina bifida and to perform research into these disorders.

### Autism Spectrum Disorders (ASD)

Over the past two decades the rate of diagnosis of autism has skyrocketed, going from perhaps 1 in several thousand to current estimates of about 1 in 90. The autism spectrum disorders (ASD) are characterized by problems in communication, social competence, and restricted interests or patterns of behavior. At the most complex level, individuals can be non-verbal and have little or no interest in their surroundings. As more research has been focused on these disorders, health professionals have discovered associated problems with sleep, gastrointestinal (GI), neurologic and immune issues. The treatment options are limited, expensive and hard to obtain, making this an often overwhelming condition for families to manage. In addition, the unprecedented increase in referrals for evaluations has taxed programs across the country, with waiting lists often extending six to nine months or more.

The Child Development Center and Center for Autism Spectrum Disorders (CASD) at Nationwide Children's has responded to this rapidly growing population by expanding its staff and the scope of services they provide. Under the leadership of Drs. Ratliff-Schaub, Eric Butter and Jacquie Wynn, they have addressed the long wait times and developed innovative ways to bring families in for initial evaluation. They have presented this model for care at national meetings and provided consultation to other medical centers dealing with ASD. The diagnostic team in the Child Development Center involves developmental pediatricians, neurologists, nurse practitioners, pediatric psychologists, occupational therapists and speech pathology. Dr. Wynn's intensive behavioral treatment program has continuously evolved, growing capacity and more specific treatment modules



that allow more children and families to access services. This past year the Child Development Center became a member of the Autism Speaks Autism Treatment Network, a consortium of programs across the U.S. and Canada working to establish best practices for treating ASDs. There are multiple research activities underway as part of this network, as well as activities that are based solely here.

### Down syndrome

Down syndrome is caused by an extra chromosome 21 and is also referred to as Trisomy 21. The presence of this extra chromosome results in a syndrome with a characteristic facial appearance and many physical conditions such as low muscle tone, small ears and mouth, and a single palmar crease. In fact, Down syndrome is the most common single cause of human

birth defects. The more serious complications include heart defects, GI defects, and increased risk of developing hypothyroidism, leukemia, and dementia. The majority of individuals with Down syndrome have low cognitive abilities or intellectual disability. There are numerous other medical conditions that occur more frequently than in the typical population, and proper care requires close monitoring for the development of such problems. The Down Syndrome Clinic at Nationwide Children's is a family-centered clinic providing diagnostic and treatment services to children and adolescents with Down syndrome and their families. These include a comprehensive medical assessment with special attention to the unique medical problems that can occur. The clinic links families with medical, educational, social and financial supports in their communities and maintains close contact with the child's primary care physician.





The Down Syndrome clinic at Nationwide Children's was established in 1999 and is under the direction of Dr. Patricia Nash. The clinic team includes a nurse coordinator, Help Me Grow specialist, psychologist, occupational therapist, physical therapist and speech and language pathologist. The psychologist helps families with some of the behavioral problems seen, such as frustration and compulsive behaviors. There are speech therapy programs geared to helping language skills and physical therapy can help with movement skills. Genetic counselors are available as needed. Recently the program has worked to coordinate services with a new Down syndrome program at the Ohio State University Medical Center, thus providing these patients and families with

**The Williams Syndrome Program at Nationwide Children's is a collaborative program with the Nisonger Center for Developmental Disabilities on the Ohio State University campus. Nationwide Children's Williams syndrome team is one of eight nationally, with families coming from across the Midwest for evaluation and care.**

health care across the lifespan. Dr. Nash has collaborated with cardiologists at Nationwide Children's to examine factors associated with pulmonary hypertension, and the clinic has been a site for clinical trials of medicines to treat the cognitive difficulties. The Down syndrome program is part of a consortium of similar clinical programs in the Mid-West that is developing a research agenda and patient registry.

#### **Williams syndrome**

Williams syndrome, also known as Williams-Beuren syndrome, is a rare genetic disorder which occurs in approximately 1 in 8-10,000 births. It is caused by a deletion of a small section of chromosome 7 and

results in the loss of approximately 25 genes that are responsible for the findings seen in the syndrome. Like Down syndrome, individuals with Williams syndrome have a characteristic facial appearance such that often the physician can make the diagnosis on examination. Genetic testing confirms the diagnosis. Common conditions seen in the syndrome include cardiac problems such as supravalvular pulmonic stenosis, high blood calcium abnormalities in infancy, and developmental delay. Most individuals have mild to moderate intellectual disability.

A typical pattern for persons with Williams syndrome is to have delayed development, including speech. As they mature, many become very talkative, outgoing and gregarious. They also display learning disorders, and often learn better through hearing than by reading. This cognitive profile is of great interest to cognitive researchers. Research is underway examining the deleted genes in Williams syndrome and contrasting this with the decreased speech and minimal social skills seen in individuals with autism spectrum disorders and with learning disabilities. The Williams Syndrome Program at Nationwide Children's is a collaborative program with the Nisonger Center for Developmental Disabilities on the Ohio State University campus. Nationwide Children's Williams syndrome team is one of eight nationally, with families coming from across the Midwest for evaluation and care. The team consists of a developmental pediatrician, psychologist, occupational therapist, physical therapist, speech and language pathology, and social work. In our program, Dr. Daisha Seyfer and Dr. Marilee Martens have conducted research on the use of medications to treat ADHD in Williams syndrome, as the possible adverse effects of these medicines can affect blood pressure and possibly the heart. They have also studied behavioral conditions such as ADHD and anxiety in these children and adolescents.

The specialized programs in developmental disabilities described here are just a few of the clinical programs in Developmental and Behavioral Pediatrics at Nationwide Children's that exemplify how, when treating children with uncommon and complex conditions, everything matters.

# Pharmacy Initiative Positively Impacts Patient Readmissions

**Thad Franz, PharmD**, Outpatient Pharmacist

In July of 2010, Nationwide Children's Hospital Outpatient Pharmacy started an initiative which focused on encouraging asthma patients to receive their medications before discharge from the hospital. This initiative complemented Nationwide Children's overall goal to decrease asthma hospital readmissions by 50 percent before January 2012.

The National Institutes of Health Asthma Guidelines recommend a focus on discharge education for asthma patients going home on medications. The benefit of filling the discharge medications at the Nationwide Children's Hospital Outpatient Pharmacy include:

- Patients leave with medication(s) in hand to increase overall compliance.
- Specialty-trained pediatric pharmacists fill, check, and dispense the patient's asthma medications. Outpatient pharmacists check all discharge prescriptions with the inpatient medical record to make sure medications are appropriate for discharge.
- All patients are counseled by a trained pharmacist or pharmacy intern and are provided additional resources to increase their knowledge and confidence with the management of their medications.

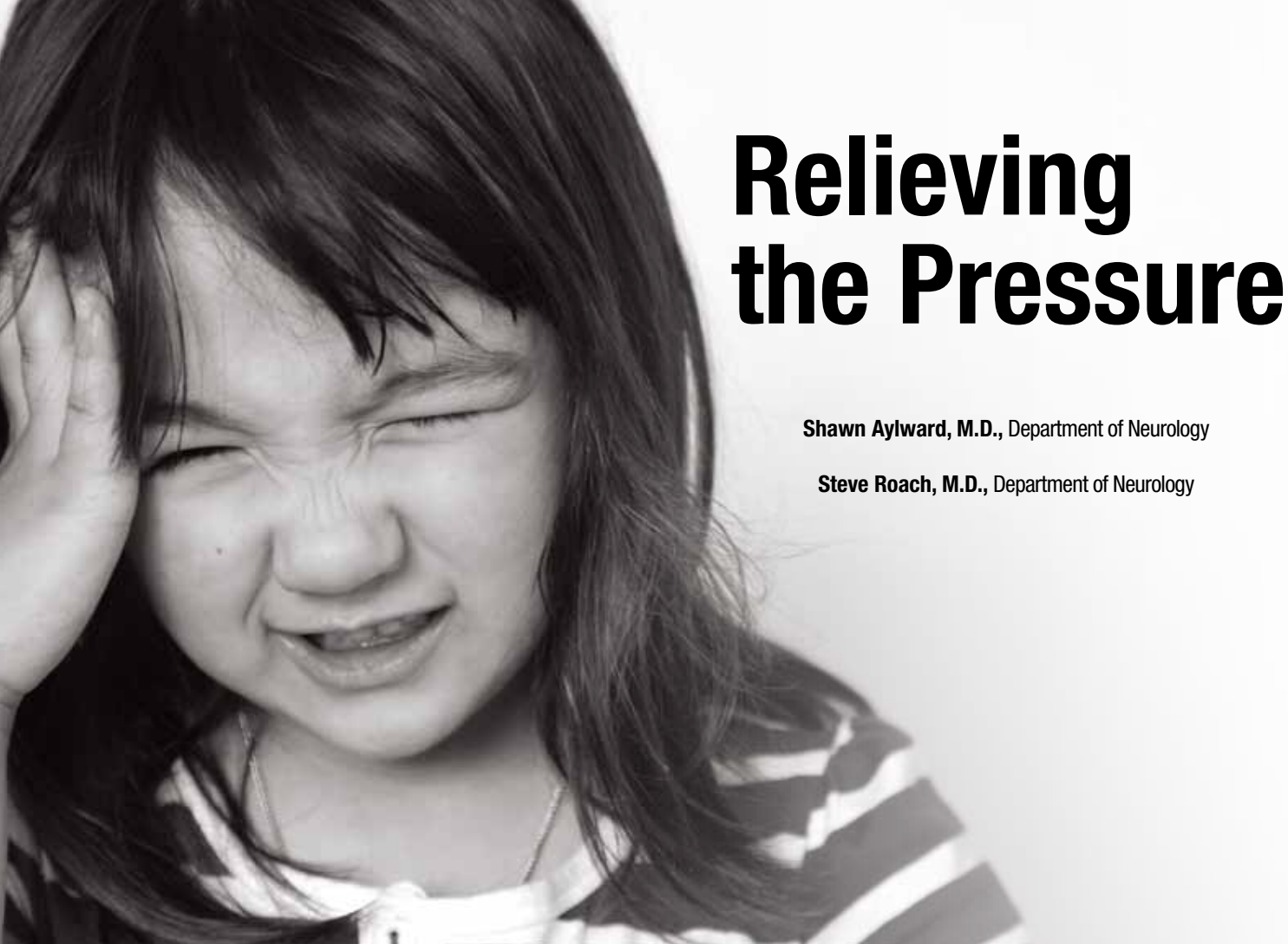
Data has shown that filling medications at the Nationwide Children's Hospital Outpatient Pharmacy upon discharge has an impact on hospital readmissions. Our efforts focus on increasing awareness of the

pharmacy services provided to the staff and patient families. Staff is made aware of the initiative through in-services which explain the benefits of encouraging patients to have their medications in hand upon discharge. Daily rounds are made by our outpatient pharmacist to ensure patients and families are aware



of the service and we provide an opportunity for them to ask questions. These efforts produced more than a 30 percent increase in asthma patients filling at the outpatient pharmacy, as well as a significant impact on decreased hospital readmissions. As we look to the future and the opening of Nationwide Children's new hospital tower, which will house an additional outpatient pharmacy, we have an opportunity to make an even larger impact on our patients. We plan to expand the "Don't Leave Without Them" concept to other populations and locations within the inpatient and outpatient settings of Nationwide Children's.





# Relieving the Pressure

Shawn Aylward, M.D., Department of Neurology

Steve Roach, M.D., Department of Neurology

Idiopathic intracranial hypertension is more commonly known as pseudotumor cerebri. It is a condition resulting from increased cerebral spinal fluid (CSF) pressure without evidence of hydrocephalus or intracranial mass. This elevation in pressure leads to the common symptoms of headache and visual deficits. The annual incidence of idiopathic intracranial hypertension among all age ranges in the United States is estimated at 0.9 per 100,000. Common risk factors for developing idiopathic intracranial hypertension include obesity (especially recent weight gain), polycystic ovarian syndrome, recent meningitis, sinus venous thrombosis, or use of some medications such as growth hormone, steroids and acne medications. The common adult patient demographic for idiopathic intracranial hypertension is an obese female. In the pediatric population, we have found this demographic comprises a small proportion of our patients. A purely clinical observation is that there appears to be two

prevalence peaks. We have observed a peak around 3 to 5 years old and again at 13 to 17 years old. Pre-pubertal children do not have a sex predilection and weight is commonly not a risk factor. Post-pubertal children tend to mirror the adult incidence.

The classic symptoms of idiopathic intracranial hypertension include a history of recent onset of daily, pulsatile, frontal headaches that are often worse when lying down or in the morning. Maneuvers that increase intracranial pressure such as coughing, Valsalva maneuver or bending over can worsen these symptoms. Other common symptoms include tinnitus often described as a whooshing or ringing sound, blurred vision, transient visual obscurations, and neck stiffness. Less frequent symptoms include vertigo, nausea and vomiting. Physical exam should not reveal any neurologic deficits with the exception of cranial nerve palsies. Sixth-nerve palsy is the most common

followed by third-, fourth-, seventh- or twelfth-cranial-nerve palsy. Sixth-nerve palsy is the inability to abduct or turn out the eye. Edema or swelling of the optic nerves, sometimes called papilledema, should be seen on exam.

The modified Dandy criteria have been adopted from the adult population for use in pediatrics. These criteria stipulate that a patient with idiopathic intracranial hypertension must have:

1. Signs and symptoms of increased intracranial pressure
2. Nonfocal neurological exam with the exception of cranial nerve palsy
3. Elevated CSF pressure, e.g. > 25cm of H<sub>2</sub>O with unremarkable CSF studies
4. Exclusion of other causes of idiopathic intracranial hypertension such as a mass lesion, hydrocephalus, or vascular malformation via imaging studies

Currently accepted standards for normal CSF opening pressure for a lumbar puncture is less than 20cm H<sub>2</sub>O. The 20 to 25cm H<sub>2</sub>O range is of unclear clinical significance and often depends on patient habitus and clinical picture. By convention, the opening pressure is measured in the left lateral decubitus position, legs and head extended to a neutral position with the patient calm and relaxed.

At Nationwide Children's, we have developed the first multidisciplinary clinical approach to treating idiopathic intracranial hypertension, called the Pseudotumor Cerebri Clinic in the Department of Neurology. The core group of practitioners includes Neurology and Ophthalmology with contributions from the departments of Neurosurgery, Healthy Weight and Nutrition, Hematology, Psychology, Endocrinology and The Ohio State University Department of Ophthalmology. Through this

collaboration, we have been able to reduce the morbidities associated with idiopathic intracranial hypertension. Initial treatment is often twice daily doses of acetazolamide and correction of any contributing risk factors. Patients receive routine follow-up visits to monitor resolution of the disease. Should patients fail medical management, or have severe progression of the disease at presentation, we are able to offer optic nerve sheath fenestration

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**We have developed the first multidisciplinary clinical approach to treating idiopathic intracranial hypertension... we have been able to reduce the morbidities associated with idiopathic intracranial hypertension.**

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or ventriculoperitoneal shunt surgeries. The type of surgical procedure chosen is case dependent. Typically, optic nerve sheath fenestration is used when there is concern for injury to the patient's vision. A ventriculoperitoneal shunt is used in cases where pain is the most prominent symptom.

If properly treated, the literature suggests favorable outcomes for patients with this disorder. Up to 20 percent of patients have some degree of visual deficit at the time of diagnosis, typically loss of visual acuity. It is reported that 10 percent of these patients have a permanent deficit. Recurrence of idiopathic intracranial hypertension is estimated to be around 20 percent. Typically this is in those where weight was a contributing factor and they failed to achieve or maintain the goal weight. Preliminary outcomes of our clinic mirror these estimates.

# Recognizing a Conversion Disorder

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Conversion disorder is a condition in which symptoms and deficits in voluntary motor and/or sensory function suggest a neurologic or physical condition but are without organic or physiologic explanation. In simpler terms, conversion disorders are physical symptoms which are caused subconsciously by psychological stress. A conversion disorder may present as problems with walking or balance, apparent weakness of limbs, tremors, pseudoseizures (seizure behaviors with normal EEG activity), or loss of vision, speech, or hearing. It is a type of somatoform disorder. Milder forms of somatization are common; many children complain of stomach aches before test taking, and we have likely all experienced headaches, “butterflies in the stomach”, nausea, or other physical symptoms during times of excessive stress. In conversion disorders, the symptoms of stress are manifested physically and, in patients lacking more appropriate stress responses, these symptoms continue or worsen if left untreated.

While conversion disorder may present at any age, it is most common in children between the ages of 10 to 15 years, and is rarely seen in children younger than six. Girls are more commonly affected than boys. Children who are depressed, who are high achievers in school or sports with high or unrealistic personal or family expectations, and those who have been victims of sexual abuse are particularly at risk.

Symptoms often appear around identifiable life stressors. Proficiency testing and other school exams may trigger an event. Parental separation or divorce,

death of a friend or family member, or major sporting competitions may also initiate physical symptoms. Upon careful history taking, one often finds that the patient has shown limited prior coping strategies, poor interpersonal communication skills (especially in males), or recurring family conflicts (more typical for females). History may also demonstrate the presence of a medical model, someone close to the patient who has had similar symptoms from a physical illness.

In true conversion disorders, the patients are unaware that the symptoms are psychological. Symptoms feel real to the patients, and they have little control over them. They are not “faking”. Malingering is the term used for symptoms which are consciously feigned. In contrast to conversion patients, malingerers may become hostile when questioned or confronted.

Many clues during physical examination may suggest a conversion disorder. The quality of weakness on testing may be ratchety, or “give-way”, which describes poor effort rather than true weakness. Inconsistency in symptoms may also be seen. For example, a child appears unable to move the legs to walk, but readily boosts himself up in bed. A patient with an apparent balance problem may stand with feet close together or in a forward flexed posture and sways dramatically but does not fall. Symptoms may be exaggerated when the child is aware he or she is being examined but improve when distracted.

In some cases symptoms may mimic organic causes so closely that testing is necessary to rule out disease. For



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example, the diagnosis of pseudoseizures may require a normal EEG during an episode to confirm. Weakness of the legs may necessitate an EMG or spine imaging to reassure family and treatment team. In many cases, however, the physical examination alone is sufficient to confirm the diagnosis of conversion disorder. Once the diagnosis is made, all further testing should stop. Extensive testing is expensive, may have adverse side effects, and reinforces the notion that an obscure or unlikely diagnosis may still be present. It is important to note that a child with an organic illness may also have an overlying conversion disorder.

While mild cases may respond to reassurance by the pediatrician, prolonged or severe symptoms may require more intensive treatment. The Rehabilitation Program at Nationwide Children's has a long record of success in treating gait abnormalities which result from conversion disorders. The protocol involves concurrent physical and psychological therapies. Physically, the patient is limited to activities which they can do proficiently, and they move through progressively more challenging motor

skills as each level is mastered. Positive reinforcement is used to promote success. At the same time, the child and family participate in psychobehavioral therapies, exploring sources of stress and learning more appropriate responses to future stressors.

Sensory, pain, and pseudoseizure manifestations of conversion disorders respond better to a psychiatric approach to treatment, combining psychobehavioral therapies with medications.

In treating these patients, one must recognize that children who do not learn appropriate stress responses are at risk for recurrence, persistence, or substitution of symptoms. Children who have shorter duration of symptoms generally have the best outcomes, typically with complete resolution of the symptoms. It is important to remember the subconscious nature of symptoms. Little is gained by confronting patients. The treatment team and the family alike should avoid labeling, trivializing, or reinforcing symptoms; instead, we need to create an expectation of recovery with the patient and the family.



# TRIPLE P – POSITIVE PARENTING PROGRAM: An Evidence-based Program for Parents of Children with Challenging Behaviors

Michelle Byrum, RN, MSN, CPNP, Certified Pediatric Nurse Practitioner; Developmental and Behavioral Pediatrics

“I have tried everything, and nothing seems to work.” This is a frequently heard statement from parents of children with difficult behaviors. The majority of parents strive very hard to raise children who are compliant, respectful, and successful. Unfortunately, some children display behaviors which are contrary to these goals, resulting in parents who become overwhelmed and stressed. In these situations, it is sometimes prudent for the parent to participate in a parent training program, which helps parents learn how to encourage positive behaviors and effectively manage difficult behaviors. Dr. Rebecca Baum, Director of the Behavioral Medicine and Consultation Clinic explains, “When a child’s behavior becomes challenging, parents may find themselves spending most of their time paying attention to negative behavior. While the parent is working really hard to

improve the child’s behavior, this type of attention may actually make things worse. Parents often need help understanding reasons why children misbehave, figuring out ways to encourage desirable behavior, and successfully addressing misbehavior when it occurs.”

There are a number of parenting programs that exist for the purpose of helping parents manage challenging behaviors. At Nationwide Children’s, we offer Incredible Years, Parent Child Interaction Therapy (PCIT), Active Parenting, and Triple P. While all of these programs are effective and evidence-based, the purpose of this article is to elaborate on the Triple P program.

The Triple P – Positive Parenting Program – is an evidence-based, multi-level intervention for reducing behavioral, emotional, and developmental problems in

children. The goal of Triple P is to equip parents and families with the knowledge and the skills necessary to manage challenging behaviors. The program draws on principles of social learning, cognitive-behavioral therapy, and developmental theory, integrating each into a cohesive and comprehensive parenting intervention. Triple P was developed by professor Matt Sanders, PhD, from the Parenting and Family Support Centre in the School of Psychology at the University of Queensland. Since its development, the Triple P program has been adopted by several government agencies around the world as their standard for parenting intervention.

Triple P aims to provide parents with just the right amount of intervention, while maintaining efficiency and cost-effectiveness. It accomplishes this goal through its use of levels of intervention that are each of increasing intensity. The different levels of Triple P also allow the provider to tailor the intervention to best meet the needs of the family.

Level 1 is a population dissemination model, which uses print and electronic media to increase awareness of parenting resources and the need for a structured approach to parenting. An example of a Level 1 approach might be the placement of signs on public transportation which recommend that parents spend five to 10 minutes per day of uninterrupted play time with their child. Also on this sign would be a phone number to contact for further parenting assistance.

Level 2 is an intervention that targets specific, mild behavioral difficulties. This may be in the form of a brief parenting seminar led by a professionally trained behavioral specialist. Another Level 2 intervention would be the provision of handouts pertaining to specific behavior problems. Triple P has developed tip sheets that can be provided to families in clinic, and target problems such as tantrums, hitting, bedtime issues, and lying.

Level 3 is a model designed for primary care. It is a brief, four-visit intervention targeting a specific mild to moderate behavior problem. This model is designed for the clinician to meet with the parents over a course of four weeks, and uses a combination of tip sheets, videos,

and active skills training to enable the parent to more effectively manage the behavior.

Level 4 is an intervention designed for more difficult or severe behavior problems. Level 4 can be delivered in an individual or group format. It generally lasts eight to 10 weeks and covers many types of behavior, rather than one specific problem. Behaviors may include aggression, meltdowns, running away in public and self injury. Level 4 is available for typically developing children, as well as children with intellectual and developmental disabilities.

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The group format is a common model in parenting interventions for difficult behaviors. David Michalec, PhD at the Child Development Center (CDC) at Nationwide Children’s, says, “We find that the group model is especially important because of the support it offers to parents. Parents realize that they are not alone. Our participants see that other families of children with disabilities have the same challenges and the same joys. Parents are also great resources of local information and tell each other about local support groups, social events, and recreational activities geared for their child.”

Level 5 is for parents who are also experiencing relationship conflict, depression, or extremely high levels





# Hand Hygiene Compliance Success at Nationwide Children's

Rich Lisciandro, RN, BSN, Accreditation Auditor, Quality Improvement Services Department

of stress. This intervention would be in an individual consultation format and is in addition to the completion of a Level 4 intervention.

Nationwide Children's is pleased to offer the Triple P parenting intervention in a number of different models and settings. The Behavioral Medicine and Consultation Clinic (BMCC) offers Triple P Level 3. This parenting program targets families of children already seen in BMCC, who are in need of an intervention of moderate intensity. Over the course of four visits, the clinician works with the parents to assess, monitor, and change a specific problem behavior.

The Center for Autism Spectrum Disorders (CASD) also offers Triple P Stepping Stones, targeting parents of children with an Autism Spectrum Disorder who also have disruptive behaviors. Like the Stepping Stones group at CDC, it is a group program where parents meet together to discuss behavior problems and solutions. The CDC offers Triple P Stepping Stones, which is a Level 4 intervention that is specifically developed for parents of children with intellectual and developmental disabilities. The CDC offering of Stepping Stones is an eight week group program with six group sessions and one individual session. Usually there are between eight

and 15 parents, and the sessions are delivered without the child in attendance. "Triple P Group Stepping Stones is important because many children with a developmental disability also have coexisting behavioral challenges. These behavioral challenges can negatively impact many spheres of functioning including family life, sibling relationships, school performance, and public behavior. Unfortunately, significant behavioral problems can interfere with treatment from therapists and teachers. The Triple P Group Stepping Stones program is uniquely tailored to meet the needs of these families. It is important to note that this program works! Research has shown many positive results for families and children. The Child Development Center is also collecting data to measure effectiveness for our groups," reports Michalec.

The Triple P – Positive Parenting Program is extremely helpful for families who need additional guidance in the promotion of positive parent-child interactions and in managing difficult behaviors. Triple P's model is unique in that it provides the opportunity to deliver an intervention to many groups of people, from an entire population group to a single mother and her child. For the parents, the experience builds confidence in their ability to effectively reduce negative behaviors, while improving relationships.

Hand hygiene compliance at Nationwide Children's was below expectations. Compliance ranged from 50.0 percent to 61.8 percent from April 2010 through August 2010. Initial efforts to improve compliance were achieved with some success. Efforts included incentives through hospital-wide competitions where the unit with the highest compliance rate won catered lunches. We also provided more easily accessible gel dispensers. However, the increased rate of 75.5 percent to 78.0 percent from September 2010 through October 2010 was not considered acceptable.

Due to consistent unacceptable results, a safety summit regarding hand hygiene was held on October 27, 2010. It was led by Nationwide Children's Chief Medical Officer Dr. Richard Brill and Chief Nursing Officer Linda Stoverock. Each leader from every hospital unit and department, along with medical staff leadership, attended the summit. During the meeting, Dr. Brill introduced the idea of each unit conducting a military-style Stand Down.

On November 4, 2010, all 24-hour operating departments were to conduct two 15-minute Stand Downs to address barriers to improved hand hygiene. Staff members were to be prepared to discuss areas for improvement and review consequences for non-compliance. Action plans were to be easily attainable and have the ability to be implemented within one week. All plans were submitted on November 9, 2010.

Enhanced monitoring of hand hygiene practice began November 15, 2010. Volunteers from the Quality Improvement Services (QIS) department visited all hospital departments and units. The volunteers covered

all shifts and weekends during a month long period. During the observations, QIS staff were expected to observe the full cycle of hand hygiene, upon entry to the patient room and then upon exit. Individuals were considered non-compliant if they missed the opportunity for hand hygiene at any point of the cycle. The volunteer auditors were required to obtain the name of all non-compliant staff and, after informing staff that they were non-compliant, coached proper hand hygiene practice. It was also an expectation that the names of the non-compliant individuals would be forwarded to Dr. Brill or Linda Stoverock so that they could address the issue with the involved individuals.

The success of hand hygiene compliance has since been celebrated at Nationwide Children's. We have maintained eight consecutive months of compliance rates of 91.0 percent or better. However, in July our rates decreased to an unacceptable level 77.9 percent. Upon further analysis, we recognized the contributing factors. In February, we decreased the number of audits and stopped collecting names of non-compliant staff. This is when the number of units with 100 percent compliance began to decrease. We did not concentrate on these units with lower compliance. We feel these factors contributed to the July results. Since then, we have refocused our efforts to communicate our hand hygiene expectations. We have increased auditing, readdressed the importance of holding staff accountable and provided positive reinforcement through small tokens of appreciation. By refocusing our efforts and communicating with staff our expectations, our compliance has returned to an acceptable level. We know with the initial and sustained results that the Stand Down was considered important by Nationwide Children's staff.

# The Complex Health Care Program

Tammy Childers, APN, Clinical Services and Care Coordination / Complex Health Care Program

In 2006, Nationwide Children's began a quality improvement initiative to improve the care experience for patients with chronic, complex illness with multiple providers. The Complex Health Care Team is growing both in team members and functionality due to this initiative. Prior to the improvement initiatives, the team consisted of a nurse practitioner and a social worker who worked together to provide additional support and care coordination to children with multiple complex health care needs and their families. Since the



arrival of the Complex Health Care Program Medical Director Dr. Garey Noritz, our team has grown to include a physician, nurse practitioner, social worker, nurse and administrative assistant. The Complex Health Care Clinic is now operational two half days a week on Wednesday afternoons and Friday mornings.

## Our Mission

The Complex Health Care (CHC) program provides service that is holistic, coordinated, continuous and family-centered to patients with complex problems. The patient and the family are the most important members of the care team. The patient and the family are the key drivers along with the primary care provider and an often extensive network of specialists. The goal is to assist the patient and the family in achieving the best possible state of health and quality of life.

## Models of Care

The CHC program offers the following models of care options: the medical home, the medical home away from home, collaboration with existing comprehensive disease specific programs such as Cerebral Palsy Clinic and Spinal Muscular Atrophy Clinic, and assistance and planning for transitioning to adult models of care.

The medical home is a family-centered approach to care that is accessible, coordinated, compassionate, continuous, comprehensive and culturally sensitive. It is a wrap-around style of care that includes all primary care needs and collaboration with specialty care providers as needed. The CHC team aims to provide a consistent point of access providing continuity that reduces fragmentation of care.



The medical home away from home includes all that is mentioned above with the patient and family receiving primary care outside of the CHC clinic. The CHC team strives to ensure communication and involvement among the primary care provider, Nationwide Children's providers and staff and patient and family.

Specific disease program collaboration with the CHC team assists with complex care needs including consultation surrounding a medical, psychosocial or care coordination issue identified by the patient, the family or the physician.

## Goals and Benefits of the Complex Health Care Program

Care for the complete needs of the child and family including medical, social, spiritual and quality of life, remains the goal of the CHC program. Patients with chronic medical problems affecting multiple body systems often have functional limitations, neurocognitive delay, dependence on technology and increased risk for frequent hospitalizations. Many specialists are involved in providing care and treatment options to the patient and the family. The

**The CHC team assists patients and families in becoming the most informed users of the available medical services, allowing them to make care choices consistent with their goals.**

CHC team assists patients and families in becoming the most informed users of the available medical services, allowing them to make care choices consistent with their goals. Additional services include support during hospitalizations, resource navigation, advocacy, transition planning and support for self-management.

Nationwide Children's CHC team is available to patients and families by phone 24/7 and sick visits can be arranged within 24 hours if needed on non-scheduled clinic days.



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