To provide optimal support and interventions for women and families facing the birth of a child with a congenital anomaly, the Multidisciplinary Fetal Care Group at MassGeneral Hospital for Children (MGH/fC) offers coordinated care plans that begin at diagnosis. Every family is seen by a personalized interdisciplinary care team that can include specialists from maternal-fetal medicine, pediatric surgery, neonatology, cardiology, orthopedics, neurosurgery, radiology, pediatric intensive care, genetic counseling, social work and palliative care depending on the specific diagnosis, its implications and the needs of the family. MGH/fC is a distinct—yet integral—part of Massachusetts General Hospital, therefore, both baby and mother are cared for at one location throughout gestation, delivery, postnatal interventions and ongoing monitoring or treatment.

**Coordinated, Proactive Care Plans Include Medical and Psychosocial Support**

The initial evaluation of a fetus with a congenital anomaly includes a targeted ultrasound by maternal-fetal medicine specialists with advanced training in ultrasound and prenatal diagnosis. When the ultrasound detects a structural abnormality or raises concern for a genetic syndrome, the multidisciplinary care team works with parents to educate them about their baby’s condition and to determine the best course of treatment both before and after the baby’s birth. The care team coordinates with additional specialists as needed to develop a personalized treatment and follow-up plan. As part of their proactive care planning, parents expecting a child who may need intensive care meet with members of the newborn intensive care unit and view the unit.

Following birth, premature and critically ill children with complex congenital conditions have access to the most advanced technological and therapeutic resources, including extracorporeal membrane oxygenation (ECMO) for reversible respiratory failure and inhaled nitric oxide for pulmonary hypertension, respiratory distress, congenital diaphragmatic hernia and other conditions. MGH/fC pediatric surgeons are experienced in the care of neonates and infants with a full range of congenital spine and brain malformations and disorders, cardiac anomalies, craniofacial abnormalities and abdominal and thoracic problems.

In addition to the most advanced medical diagnostic procedures and treatments, parents have rapid access to a perinatal social worker who provides clinical guidance and support following diagnosis of a complicated pregnancy. In addition, a social worker who is board-certified in palliative care is available to parents who have received diagnosis of a potentially life-limiting condition for their...
Maternal Fetal Medicine: Lifetime Family Care Begins at Diagnosis for Congenital Anomalies
Continued from page 1

child. With the help of palliative care, parents can assess the degree of certainty in their child’s outcome, consider their options for the pregnancy and grieve the repercussions of the diagnosis and outcome. This approach, says Patricia O’Malley, MD, medical director of the Pediatric Palliative Care Service and unit chief emerita of Pediatric Emergency Services, uses newer understanding of grief and attachment to help families explore their emotional connection to the fetus. Contrary to early understanding of attachment and grief, research indicates that supporting attachment can facilitate healthy grieving.

Developmental Biology Studies Pave the Way to Improved Treatments

Children with birth defects fill one third of the hospital beds in children’s hospitals the United States. While significant advances in neonatal care have improved outcomes for these young patients, MGH/C clinical researchers study normal development in model systems with the goal of understanding how these processes go awry in congenital abnormalities. For example, studies of Hirschsprung’s disease by Allan Goldstein, MD, and Jaime Belkind Gerson, MD, at MGH/C have led to the ability to grow functioning enteric neurons and glial cells in vivo and then to transplant the cells into a mouse model of Hirschsprung’s disease. MGH/C have led to the ability to grow functioning enteric neurons and glial cells in vivo and then to transplant the cells into a mouse model of Hirschsprung’s disease. MGH/C is one of only a handful of research centers worldwide conducting this type of research. Ultimately this work may lead to the ability to replace the missing neurons in children with Hirschsprung’s disease.

Orofacial clefts such as cleft lip and palate are the most common structural birth anomalies. Each year, the MGH/C Cleft Lip and Craniofacial Clinic sees individuals with orofacial clefts in addition to providing comprehensive, multidisciplinary care for people of all ages with craniofacial disorders. Studies in the Craniofacial Developmental Biology Laboratory directed by surgeon-scientist Eric C. Liao, MD, PhD, support advances in clinical care by investigating the genetic regulation of facial development. Using the genetically tractable zebrafish model, Dr. Liao and his team at the Center for Regenerative Medicine have characterized the role of the Wnt signaling pathway and characterize candidate genes for CDH and gene variants shared in patients with both diaphragm and heart anomalies. Lung development studies led by surgeon researcher Cassandra Kelleher, MD, have led to creation of an organ culture model that allows for the study of the molecular mechanisms involved in postnatal alveolar development. Impaired alveolar development leads to lung hypoplasia in newborns and infants with congenital diaphragmatic hernia, cystic lung lesions and brochopulmonary dysplasia. This model system allows MGH/C researchers to study non-invasive pharmacologic approaches to enhance maturation of hypoplastic lungs in utero, potentially improving survival and reducing long-term complications.

For more information about the Maternal-Fetal Medicine Program at MGH/C, please call 617-724-2229.

In January 2013, the Center for Celiac Research moved from the University of Maryland School of Medicine to MassGeneral Hospital for Children (MGH/C), where investigators will continue studies of the development and treatment of gluten-related disorders in patients of all ages under the leadership of Alessio Fasano, MD. Dr. Fasano, chief of Pediatric Gastroenterology and Nutrition, also directs the Mucosal Immunology and Biology Research Center and is associate chair of basic, clinical and translational research for the Department of Pediatrics at MassGeneral Hospital for Children. He treats both adults and children with celiac disease and other gluten-related disorders. He has been named visiting professor of pediatrics at Harvard Medical School.

Dr. Fasano’s research established that celiac disease affects approximately one percent of the U.S. population, a significantly higher number than previously believed, and helped define gluten sensitivity as a condition on the spectrum of gluten-related disorders. His research also uncovered the role that impairment of the tight junctions between intestinal enterocytes plays in the development of celiac disease. During research designed to develop a choleara vaccine, Dr. Fasano uncovered a toxin, zonula occludens, which causes diarrhea by loosening the tight junctions and allowing intestinal permeability. Subsequently, he identified the protein zonulin, which controls this process. He has since established the role of zonulin in the pathogenesis of celiac disease and type 1 diabetes. Other investigators have linked zonulin upregulation with certain cancers and diseases of the nervous system. Safety and efficacy testing of a zonulin inhibitor, Lanzatide acetate, has been completed, and Alba Therapeutics—a company co-founded by Dr. Fasano—is currently conducting a phase 2B study.

In ongoing research, Dr. Fasano is investigating the composition and changes in the gastrointestinal microbiota to help determine why some individuals with an inherited predisposition to celiac disease develop clinical disease while others do not. His research team is also investigating the role of the timing of gluten introduction to infants in the development of celiac disease and working to uncover a biomarker and to develop a diagnostic tool for gluten sensitivity. Furthermore, the center is pursuing possible links between gluten-related disorders and conditions such as schizophrenia and autistic spectrum disorder in certain subgroups of patients. A native of Salerno, Italy, Dr. Fasano earned his medical degree from the University of Naples, where he also completed a residency in pediatrics. He founded the Center for Celiac Research at the University of Maryland School of Medicine in 1996 and the Mucosal Biology Research Center in 2003. Dr. Fasano has been named the 2013 recipient of the Linus Pauling Award. The Center for Celiac Research’s patient clinic opened in February 2013 in the Yawkey Center for Outpatient Care, Suite 6B, at 55 Fruit Street in Boston. For more information, please call 617-643-2225 or visit massgeneralforchildren.org/celiac.
Down Syndrome Care Spans Patient Lifetime

Mass General Hospital for Children is pleased to announce the opening of the Down Syndrome Program. Down syndrome occurs in about one of every 830 babies born in the United States each year. Yet current models of care address either pediatric issues in freestanding children’s hospitals or adult concerns in an adult medical setting with little-to-no connection between the two. This approach results in a loss of care continuity and, in some instances, patients falling through the cracks during the crucial transition from adolescence to adulthood. In most medical centers, geneticists provide prenatal counseling and education for parents expecting a child with trisomy 21, translocation Down syndrome or mosaic Down syndrome, but this care is disconnected from resources available following birth, leaving expectant parents with an incomplete understanding of the medical and psychosocial support available to them. One of the only clinics of its kind in the nation, the MGH/C Down Syndrome Program offers five separate, integrated clinics that allow medical and psychosocial specialists with expertise in Down syndrome to focus on special needs within age groups while ensuring seamless lifetime care. At one location and on one day, patients receive all the age-appropriate evaluations recommended in the American Academy of Pediatrics guidelines. Providers within the clinic facilitate referrals to other services as needed, including gastroenterology, neurology, cardiology, endocrinology, pediatrics, pulmonary/sleep medicine, ophthalmology, gynecology, orthopedics, dermatology, dentistry and psychiatry.

During clinic visits, physicians and therapists generate extensive notes that are sent to families and to care providers. A social worker attends all patient visits and follows up with families to ensure the letter has been received and addresses any questions or difficulties the family may have in implementing the care team’s suggestions. Families experiencing particular difficulties connecting to appropriate resources receive ongoing support and communication.

Multidisciplinary Clinics for Prenatal Through Adult Patients

Expectant parents meet with either of the program’s co-directors, medical geneticist Brian Skotko, MD, MPP, or pediatrician and internist Allie Schwartz, MD, along with a genetic counselor and social worker. The team counsels families undecided about their pregnancy options and answer questions, or, if parents have elected to proceed with the birth, the prenatal sessions can help them prepare to meet their child’s needs. If desired, parents can also meet with the clinic’s self-advocate resource specialist, Ben Majewski, who has Down syndrome.

Infant and Toddler Clinic

Between birth and age 5, patients are seen in the infant and toddler clinic by a physician with expertise in Down syndrome, social worker, nutritionist, physical therapist, occupational therapist, speech-language pathologist, program coordinator, audiologist and ophthalmologist. The resource specialist also participates in the visit, letting parents know of his own experiences or providing candid information on particular topics relevant to the family. The physical therapist, occupational therapist and speech therapist evaluate the patient’s individualized education plan (IEP) or individualized family service plan (IFSP) and, based on their overall assessment of the child, provide specific recommendations that can be implemented at home and with home therapy teams.

Clinic for Patients Ages 5-13

From age 5 to 13, the same specialists provide care as in the infant and toddler clinic, and a psychologist from Mass General’s Psychology Assessment Center (PAC) joins the team. The primary goals of this clinic are comprehensive health care and school success. PAC provides neuropsychological and psychological evaluations to patients with cognitive or emotional difficulties across the lifespan and provides educational liaison services for children, including school consultations. The psychologist can help families intervene appropriately in behavioral issues and identify other health diagnoses that may require further treatment. If needed, team members can facilitate referrals to other resources and specialists, including Mass General’s Lurie Center for Autism.

Clinic for Patients Ages 13-21

Support and education for transition planning, including self-care and guardianship concerns, occur in the adolescent and young adult clinic, which is geared for patients ages 13 to 21. During this time, the MGH/C care team focuses on health maintenance and spends additional time assessing adolescents for possible underlying depression, anxiety, obsessive-compulsive disorder or mental health condition that may need treatment prior to independence. According to Dr. Schwartz, some individuals with Down syndrome reach legal adulthood without a guardianship arrangement despite the best efforts of the Department of Developmental Services, schools and families. The adolescent and young adult clinic is intended to provide a safety net for these patients in addition to providing comprehensive medical and neuropsychological care.

Adult Clinic

In the adult clinic, for patients 21 and older, visits routinely involve the full Down syndrome care team and may also include referrals to other specialty providers at Mass General to ensure health, quality of life and meaningful engagement with the communities for patients. Since individuals with Down syndrome are prone to early onset Alzheimer’s disease and cognitive decline, the Down Syndrome Program directors have established relationships with PAC to assist in determining whether changes in cognition and level of functioning are related to medical or neurological disorders.

Research Probes Health Trends in Down Syndrome

The Mass General Down Syndrome Program participates in a nationwide effort to build a patient registry to support identification of health trends and therapeutic opportunities for Down syndrome patients. Additionally, by seeing patients from birth through old age, the directors are able to establish a research center of excellence that will advance the understanding of the medical conditions associated with trisomy 21. Currently Dr. Skotko’s research focuses on sleep disturbances and prenatal decision making.

To schedule an appointment, call 617-643-8912 or email downsyrindrome@partners.org. For more information, visit massgeneralforchildren.org/downsyndrome.

To schedule an appointment, please call the MGH/C Access and New Appointment Center at 888-644-3211.

Allie Schwartz, MD, co-director, Down Syndrome Program, with patient.

Brian Skotko, MD, MPP, co-director, Down Syndrome Program, with patient.
Multidisciplinary Design and Care Distinguishes Youth Sports Concussion Clinic

Current management guidelines for pediatric concussion are not evidence-based, and media coverage of the effects of post-concussion syndrome has generated high anxiety in parents, young athletes and coaches. Data-driven care plans that incorporate the expertise of all specialists involved in the care of the developing brain are needed to provide the best possible care for young athletes, and factual information is needed to allay the concerns of parents and coaches.

For the past five years, the clinical affiliation between Massachusetts General Hospital and Southern New Hampshire Health System (SNHHS) has allowed children in Nashua and surrounding communities to receive specialty care from MassGeneral Hospital for Children (MGH/C) physicians specializing in endocrinology and diabetes, gastroenterology and nutrition, and pulmonology while remaining close to home. Earlier this year, MGH/C re-introduced a pediatric cardiology clinic and added neurology to its pediatric specialty offerings. An MGH/C pediatric general surgeon will be available soon. MGH/C providers see patients on an outpatient basis, are available for inpatient consults and provide 24/7 coverage for patients through the Mass General network.

To support parents whose child has already been injured, these sessions provide information that can help parents protect other children involved in youth sports, after-school athletic programs and community recreational programs. Laws requiring training in concussion management have spread from professional sports to middle-school and high-school coaches, trainers, athletes and referees, and some communities are trying to extend these efforts to younger children and parents.

Same-Day Care for Pediatric Fractures

Since 2002, the MGH/C Pediatric Fracture Clinic has provided same-day care by pediatric orthopedic specialists or musculoskeletal specialists for children with confirmed or suspected fractures of the upper or lower extremities. In addition to a board-certified pediatric orthopedic surgeon, the fracture care team may also include nurse practitioners, physician assistants, radiology technician and nurse coordinators, child life specialists and translators. This service provides a convenient and efficient alternative to emergency services for injuries not acute enough to require emergency care, reducing costs and delays while providing expert evaluation and treatment to children with simple or severe fractures.

The clinic is held daily, Monday through Friday, at the main campus in Boston, and is also available at Mass General/North Shore Center for Outpatient Care in Danvers, at MassGeneral for Children at Newton-Wellesley Hospital and at the Brigham and Women’s/Mass General Health Care Center at Foxborough.

To refer a patient, please call 617-726-8523. For more information about the Pediatric Orthopaedics program, visit massgeneralforchildren.org/orthopedics.
MGHfC Weight Management Programs: Two Locations

MGHfC weight centers located at the Newton-Wellesley Hospital and Mass General Hospital locations provide medical assessment and treatment, nutrition and exercise counseling, and psychological support for children and adolescents who are obese, at risk for obesity or who have or are at risk for weight-related problems. Physicians in the programs collaborate with specialists at Newton-Wellesley Hospital, Mass General Hospital and MGHfC to provide patients and families with comprehensive care. Indications for referral to either of these MGHfC programs include: 1) overweight and obesity (BMI at or above the 85th percentile) at any age; 2) increasing BMI percentiles over time and/or family concerns about weight gain; 3) initiation of therapies known to promote weight gain, such as steroids, psychotropic medications and tonsillectomy adenoidectomy; and 4) general concerns about risks, prevention, consequences and treatment of obesity. The Boston program is also available for consideration of weight loss surgery.

Newton-Wellesley Hospital Program for Patients Ages 11-25

Patients seen at the MGHfC Weight Management Program at Newton-Wellesley Hospital are evaluated by Jennifer Rosenthal, MD, a physician board certified in internal medicine and adolescent medicine with a specialty in obesity medicine, and by a pediatric dietitian with expertise in weight loss counseling and cardiovascular health. Dr. Rosenthal provides exercise counseling as well as expertise regarding weight loss medications. All follow-up physician appointments are scheduled in coordination with a dietitian for nutritional counseling. When appropriate, patients will be referred for additional evaluations including psychological assessment, sleep studies and assessment by other specialists from throughout MGHfC.

The MGHfC Weight Management Program at Newton-Wellesley Hospital is for patients ages 11-25. This program, which has been in place since 2006, usually accepts health insurance, including nutritional visits. Patients must be referred by a pediatrician or other provider such as a medical specialist, dietitian or therapist.

For more information, please call 617-243-6385 or 617-643-1201 or visit massgeneralforchildren.org/weight

Boston Program for Patients of All Ages

The MGHfC Weight Center in Boston represents a new partnership between MGHfC and the Mass General Weight Center to meet the medical, nutritional, psychological and educational needs of children and adolescents of any age who are overweight or obese, or who are at risk for obesity. Pediatric subspecialists in the fields of obesity medicine, endocrinology, gastroenterology, pulmonology and bariatric surgery collaborate with registered dietitians and psychologists to provide expert multidisciplinary care of children and adolescents with obesity and to support them in their efforts to achieve better health. While the primary focus of the program is on nutrition and behavioral approaches to treating obesity, weight loss medications and weight loss surgery are considered for a subset of patients with severe obesity. The MGHfC Weight Center team works closely with specialists throughout MGHfC, providing referrals for group programs, sleep studies and other consultations as needed.

For more information about the Boston-based program, please call 617-726-0373 or visit massgeneralforchildren.org/weight

New Physicians

Anesthesia

DAVID AUGUST, MD, PHD
MD degree: University of Virginia Medical School
PhD degree: University of Virginia Medical School
Residency: Anesthesiology, Massachusetts General Hospital
Fellowship/s: Pediatric Anesthesiology, Children’s Hospital Boston
Board certification/s: Anesthesiology
Clinical interests: Pediatric anesthesiology

MICHAEL LIEMAN, MD
MD degree: St. George’s University School of Medicine
Residency: Pediatrics, Tufts Medical Center
Fellowship/s: Pediatric Anesthesiology, Tufts Medical Center
Board certification/s: Anesthesiology
Clinical interests: Pediatric anesthesiology, out of operating room anesthesia, pediatric pain management

Cardiovascular Research Center

MARK LINDSAY, MD, PHD
MD degree: University of Virginia School of Medicine
PhD degree: University of Virginia
Residency: Pediatrics, Johns Hopkins School of Medicine
Fellowship/s: Cardiology, Johns Hopkins Hospital; Massachusetts General Hospital; Pediatric Cardiology, Johns Hopkins School of Medicine
Board certification/s: Pediatrics
Clinical interests: Marfan syndrome, Loos–Deitz syndrome and related disorders; diagnosis

Endocrinology

DEBORAH MITCHELL, MD
MD degree: Harvard Medical School
Residency: Pediatrics, Massachusetts General Hospital
Fellowship/s: Pediatric Endocrinology, Massachusetts General Hospital
Board certification/s: Pediatrics
Clinical interests: General pediatric endocrinology, bone and mineral metabolism

Down Syndrome Program

ALISON SCHWARTZ, MD
MD degree: Tufts University School of Medicine
Residency: Pediatrics, Internal Medicine, Massachusetts General Hospital
Board certification/s: Pediatrics, Internal Medicine
Clinical interests: Primary care, Down syndrome, transition of youth with special health care needs

BRIAN SKOTKO, MD, MPP
Co-director, Down Syndrome Program
MD degree: Harvard Medical School
MPP degree: Harvard Kennedy School
Residency: Pediatrics, Boston Children’s Hospital; Boston Medical Center
Fellowship/s: Boston Children’s Hospital, Massachusetts General Hospital, Brigham and Women’s Hospital, Medical Genetics, Dana Farber Cancer Institute
Board certification/s: Clinical Genetics (MD)
Clinical interests: Down syndrome, bosomy 21, intellectual disabilities in children, developmental delays in children, medical genetics

To schedule an appointment, please call the MGHfC Access and New Appointment Center at 888-644-3211.
New Physicians

Gastroenterology and Nutrition

ALESSIO FASANO, MD
Chief, Pediatric Gastroenterology
Director, Center for Celiac Research
MD degree: University of Naples
Residency: University of Naples
Clinical interests: Diagnosis, treatment and prevention of gluten-related disorders

INBAR (AMBER) SPOFFORD, MD
MD degree: Pennsylvania State University College of Medicine
Residency: Rhode Island Hospital/Haasbro Children’s Hospital
Fellowships: Massachusetts General Hospital
Board certification/s: Pediatrics
Clinical interests: General pediatric gastroenterology and nutrition, medical education and procedural training, pediatric therapeutic endoscopy

Lurie Center for Autism

NORA FRIEDMAN, MD
MD degree: Albert Einstein College of Medicine
Residency: Massachusetts General Hospital
Board certification/s: Psychiatry
Clinical interests: Child and adolescent psychiatry, developmental disorders, autism

General Pediatrics

ELSIE M. TAVERAS, MD, MPH
Chief, Division of General Pediatrics
Director, Pediatric Population Health Management
MPH degree: Harvard School of Public Health
MD degree: New York University School of Medicine
Residency: Boston Medical Center; Pediatrics, Boston Children’s Hospital
Fellowships: Harvard Pediatric Health Services Fellowship Program, Boston Children’s Hospital
Board certification/s: Pediatrics
Clinical interests: Childhood obesity, chronic disease prevention, maternal-child health disparities, population health, health care delivery systems, clinical-community partnerships and interventions

Hospitalist

KATHERINE WEBSTER ALTHSHUL, MD
MD degree: Tufts University School of Medicine
Residency: Massachusetts General Hospital
Board certification/s: Pediatrics

Neonatology

SARA V. BATES, MD
MD degree: University of Rochester School of Medicine and Dentistry
Residency: Massachusetts General Hospital
Fellowships: Boston Children’s Hospital
Board certification/s: Pediatrics
Clinical interests: Neonatal neurocritical care

Pediatric Group Practice

WHITNEY SCHUTZBANK, MD, MPH
MD degree: Tulane University School of Medicine
MPH degree: Tulane University School of Medicine
Residency: Pediatrics, Massachusetts General Hospital
Board certification/s: Pediatrics
Clinical interests: Pediatric primary care, childhood obesity

Pediatric Medical Services

DIANE BELDER-PRESTON, MD
MD degree: University of Ottawa Faculty of Medicine
Residency: Children’s Hospital of Eastern Ontario
Board certification/s: Pediatrics
Clinical interests: Pediatrics

Pulmonology

SZE MAN TSE, MDCM
MDCM Degree: McGill University Faculty of Medicine
Residency: Montreal Children’s Hospital
Fellowships: Massachusetts General Hospital
Clinical interests: Pediatric pulmonology

Allan Goldstein, MD, FACS, director of the Pediatric Neurogastroenterology Program, has been appointed chief of the Division of Pediatric Surgery for MassGeneral Hospital for Children (MGHfC) and will lead the division’s clinical, education, research and community service activities. Goldstein succeeds Joseph P. Vacanti, MD, who has held the position since 2003. Vacanti will remain as MGHfC’s surgeon-in-chief, with a focus on building the pediatric surgical specialties.

Since 2003, Goldstein has served as the director of the Pediatric Neurogastroenterology Program and head of the MassGeneral Neurogastroenterology Laboratory, which is focused on understanding how the intestinal nervous system develops and is organized and how it interacts with, and influences, other aspects of the intestine. Goldstein has worked extensively on researching the causes of and identifying novel diagnostic and therapeutic approaches for Hirschsprung’s disease—a serious disorder of the bowel caused by the absence of nerve cells in the large intestine.

To schedule an appointment, please call the MGHfC Access and New Appointment Center at 888-644-3211.
CME Opportunities

Frontiers in Pediatric Gastroenterology, Hepatology and Nutrition

NOVEMBER 8-9, 2013

Location:
Massachusetts General Hospital, Simches Research Center, 185 Cambridge Street, Room 3110, Boston, MA

Director:
Aeri Moon, MD

CHILD NEUROLOGY 2013

SEPTEMBER 30 – OCTOBER 4, 2013

Location:
Royal Sonesta Hotel, 40 Edwin Land Boulevard, Cambridge, MA

Course Directors:
Katherine Sims, MD, and Kevin Staley, MD

Registration:

Primary Care Pediatrics

DECEMBER 4-6, 2013

Location:
The Marriott Boston Long Wharf, 296 State Street, Boston, MA

Director:
Peter Greenspan, MD

Emergencies and Procedures in Pediatrics

DECEMBER 13–15, 2013

Location:
The Marriott Boston Long Wharf, 296 State Street, Boston, MA

Director:
Linda T. Wang, MD

For more information about these and other events, please visit massgeneral.org/children/education

massgeneral.org/children/education

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