CHRONIC COMPLEX DISEASES OF CHILDHOOD

A PRACTICAL GUIDE FOR CLINICIANS

Edited by

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Tables & Figures ............................................. xv
Acknowledgements ...................................... xvi
Contributors .............................................. xvii
Preface .................................................. xx

1 Creating the Medical Home .............................. 1

2 Cardiac Disorders ....................................... 9

Atrial Septal Defect (ASD) ................................ 10
    Gary M. Satou, Thomas S. Klitzner

Coarctation of the Aorta ................................ 13
    Gary M. Satou, Thomas S. Klitzner

Ebstein Anomaly ........................................ 17
    Gary M. Satou, Thomas S. Klitzner

Hypertrophic Cardiomyopathy (HCM) ................. 20
    Gary M. Satou, Thomas S. Klitzner

Hypoplastic Left Heart Syndrome (HLHS) ............ 24
    Gary M. Satou, Thomas S. Klitzner

Long QT Syndromes (LQTS) ............................ 28
    Thomas S. Klitzner, Gary M. Satou

Pulmonary Hypertension ................................ 31
    Gary M. Satou, Thomas S. Klitzner

Supraventricular Tachycardia (SVT)/Wolf-Parkinson–White Syndrome (WPW) ....... 35
    Thomas S. Klitzner, Gary M. Satou

Tetralogy of Fallot (TOF) ................................ 39
    Gary M. Satou, Thomas S. Klitzner

Total Anomalous Pulmonary Venous Return (TAPVR) ..... 43
    Gary M. Satou, Thomas S. Klitzner

Transposition of the Great Arteries ................. 46
    Gary M. Satou, Thomas S. Klitzner

Truncus Arteriosus ..................................... 49
    Gary M. Satou, Thomas S. Klitzner

Ventricular Septal Defects (VSD) ...................... 52
    Gary M. Satou, Thomas S. Klitzner
3 Dermatologic Disorders ................................................................. 55

Ectodermal Dysplasias .................................................................. 56
  Ronald W. Cotliar

  Hidrotic Ectodermal Dysplasia .................................................... 57
  Ronald W. Cotliar

  Hypohidrotic Ectodermal Dysplasia ........................................... 59

Epidermolysis Bullosa (EB) ............................................................ 62
  Ronald W. Cotliar

Infantile Hemangiomas (IH) ........................................................ 68
  Ronald W. Cotliar

Childhood Vitiligo ......................................................................... 73
  Delphine J. Lee

4 Endocrinologic Disorders .......................................................... 77

Adrenal Hyperplasia ...................................................................... 78
  Mitchell E. Geffner

Androgen Insensitivity Syndrome (AIS) ....................................... 82
  Mitchell E. Geffner

Craniopharyngioma ...................................................................... 85
  Mitchell E. Geffner

Diabetes (Type 1) ....................................................................... 89
  Eba H. Hathout

Diabetes (Type 2) ....................................................................... 93
  Eba H. Hathout

Congenital Hyperinsulinism (CHI) ................................................. 96
  Mitchell E. Geffner

Kallmann Syndrome ..................................................................... 99
  Mitchell E. Geffner

Klinefelter Syndrome .................................................................. 103
  Mitchell E. Geffner

Polycystic Ovarian Syndrome (PCOS) ....................................... 106
  Mitchell E. Geffner

5 Gastroenterologic Disorders ......................................................... 109

α₁-antitrypsin Deficiency ............................................................ 110
  Michelle Pietzak

Celiac Disease (CD) .................................................................. 114
  Michelle Pietzak

Chronic Diarrhea in Children, Malabsorption Syndromes, Protein Losing Enteropathy .............................................. 120
  Randall Chan, Michelle Pietzak

Crohn's Disease ........................................................................ 127
  Michelle Pietzak

Cyclic Vomiting Syndrome .......................................................... 133
  Dafna Babaeegy, Michelle Pietzak

Polyposis Syndromes (Juvenile) .................................................. 137
  Dafna Babaeegy, Michelle Pietzak

Portal Hypertension ..................................................................... 143
  Michelle Pietzak
Primary Sclerosing Cholangitis (PSC) .................................................. 148
Michelle Pietzak
Short Bowel Syndrome (SBS) ................................................................. 152
Khiet D. Ngo
Ulcerative Colitis (UC) ........................................................................... 159
Michelle Pietzak

6 Genetic Disorders .............................................................................. 165

Introduction to Genetics and Inborn Errors of Metabolism .................... 166
Stephen Cederbaum
Disorders of Small Molecules Circulation in the Blood. ......................... 167
A. Disorders Presenting with an Acute Metabolic Crisis ......................... 167
Stephen Cederbaum
B. Disorders Presenting with Chronic Metabolic Intoxication ................. 171
Stephen Cederbaum

Lysosomal Storage Disorders ............................................................... 174
Stephen Cederbaum

Disorders of Energy Metabolism .......................................................... 178
A. Glycogen Storage Disorder (Glycogenoses, von Gierke disease) .......... 178
Stephen Cederbaum
B. Disorders of Pyruvate Metabolism
Pyruvate Dehydrogenase Deficiency, Pyruvate Carboxylase Deficiency,
Pyruvate Decarboxylase Deficiency, PDH, PC, PDC ............................. 181
Stephen Cederbaum
C. Disorders of the Mitochondrial Respiratory Chain (MELAS, MERRF, Leigh disease) ..................................................... 183
Stephen Cederbaum
D. Disorders of Fatty Acids Oxidation and Carnitine Metabolism (FAOD) ..................................................................... 186
Stephen Cederbaum

Disorders of Folate and Neurotransmitter Metabolism ........................... 189
Stephen Cederbaum

Disorders of Peroxisomal Metabolism ................................................... 192
Stephen Cederbaum

Down Syndrome (Trisomy 21 Syndrome) ............................................. 195
Derek Wong

22Q11.2 Deletion Syndrome ................................................................ 199
Derek Wong

Turner Syndrome .................................................................................. 202
Derek Wong

7 Hematologic Disorders ..................................................................... 205

Neonatal and Infant Cytopenias ............................................................. 207
Stephen A. Feig, George B. Segel, Kenji Morimoto

Anemias due to Lack of Red Cell Production ....................................... 208
Stephen A. Feig, George B. Segel, Kenji Morimoto

Anemias Due to Red Cell Loss or Destruction ..................................... 211
Stephen A. Feig, George B. Segel, Kenji Morimoto

Hemolytic Disease of the Newborn (HDN) .......................................... 212
Stephen A. Feig, George B. Segel, Kenji Morimoto

Neutropenias of the Infant or Neonate ............................................... 214
Stephen A. Feig, George B. Segel, Kenji Morimoto
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thrombocytopenia</td>
<td>218</td>
</tr>
<tr>
<td>A. Thrombocytopenia Due to Decreased Platelet Production</td>
<td>219</td>
</tr>
<tr>
<td>B. Thrombocytopenia due to Platelet Destruction</td>
<td>221</td>
</tr>
<tr>
<td>Childhood Anemias</td>
<td></td>
</tr>
<tr>
<td>Hereditary Hemolytic Anemias</td>
<td>223</td>
</tr>
<tr>
<td>Red Cell Membrane Disorders</td>
<td></td>
</tr>
<tr>
<td>Red Cell Enzyme Deficiencies</td>
<td></td>
</tr>
<tr>
<td>Hemoglobinopathies</td>
<td>231</td>
</tr>
<tr>
<td>A. Thalassemias</td>
<td>231</td>
</tr>
<tr>
<td>B. Sickle Cell Anemia</td>
<td>235</td>
</tr>
<tr>
<td>Acquired Hemolytic Anemias</td>
<td>241</td>
</tr>
<tr>
<td>A. Auto Immune Hemolytic Anemias with Warm Antibodies (AIHA)</td>
<td>241</td>
</tr>
<tr>
<td>B. Auto-Immune Hemolysis with “Cold” Antibodies</td>
<td>243</td>
</tr>
<tr>
<td>C. Paroxysmal Nocturnal Hemoglobinuria (PNH)</td>
<td>245</td>
</tr>
<tr>
<td>Nutritional Anemias</td>
<td>246</td>
</tr>
<tr>
<td>Anemia of Chronic Disease</td>
<td>249</td>
</tr>
<tr>
<td>Methemoglobinemia</td>
<td>251</td>
</tr>
<tr>
<td>Aplastic Pancytopenias</td>
<td>253</td>
</tr>
<tr>
<td>Bleeding Disorders</td>
<td></td>
</tr>
<tr>
<td>Congenital Factor Deficiencies (Hemophilioid States)</td>
<td>257</td>
</tr>
<tr>
<td>Hemorrhagic Disease of the Newborn</td>
<td>262</td>
</tr>
<tr>
<td>Coagulopathy of Liver Disease</td>
<td>263</td>
</tr>
<tr>
<td>Von Willebrand Disease</td>
<td>264</td>
</tr>
<tr>
<td>Immune Thrombocytopenic Purpura (ITP)</td>
<td>268</td>
</tr>
<tr>
<td>Platelet Function Disorders</td>
<td>271</td>
</tr>
</tbody>
</table>
Common Pediatric Epilepsy Syndromes ............................................................... 395
  Raman Sankar, Christopher C. Giza

  A. Childhood Absence Epilepsy (CAE) and Juvenile Absence Epilepsy (JAE) .......... 396
  B. Benign Epilepsy of Childhood with Central-Temporal Spikes
  (BECTS, Rolandic Epilepsy) ............................................................................. 398
  C. Other Benign Localization-Related Epilepsies of Childhood ...................... 399
  D. Juvenile Myoclonic Epilepsy (JME) .......................................................... 400

Infantile Spasms (West Syndrome) ................................................................. 402
  Christopher C. Giza, Raman Sankar

The Lennox-Gastaut Syndrome (LGS) ............................................................ 405
  Raman Sankar, Christopher C. Giza

Landau-Kleffner Syndrome (LKS) ................................................................. 409
  Christopher C. Giza, Raman Sankar

Progressive Myoclonus Epilepsy (PME) ......................................................... 412
  Christopher C. Giza, Raman Sankar

  A. Unverricht-Lundborg (Baltic myoclonus) disease .................................... 414
  B. Lafora disease .......................................................................................... 415
  C. Myoclonic epilepsy with ragged red fibers (MERRF) .............................. 416
  D. Neuronal ceroid lipofuscinoses (NCL) .................................................... 417
  E. Sialidosis .................................................................................................. 419

Rasmussen Encephalitis .................................................................................. 420
  Christopher C. Giza, Raman Sankar

Headaches ....................................................................................................... 423

Migraine .......................................................................................................... 423
  Christopher C. Giza, Raman Sankar

Pseudotumor Cerebri (PTC) ........................................................................... 429
  Christopher C. Giza, Raman Sankar

Neurocutaneous Syndromes .......................................................................... 432

Neurofibromatosis ......................................................................................... 432
  Raman Sankar, Christopher C. Giza

Sturge-Weber Syndrome (SWS) .................................................................... 435
  Raman Sankar, Christopher C. Giza

Tuberous Sclerosis Complex (TSC) ................................................................ 438
  Raman Sankar, Christopher C. Giza

Neurodevelopmental Disorders ..................................................................... 442

Cerebral Palsy (CP) ......................................................................................... 442
  Christopher C. Giza, Raman Sankar

Management of Spasticity ............................................................................. 446
  Christopher C. Giza, Raman Sankar

Autism ........................................................................................................... 451
  Christopher C. Giza, Raman Sankar

Rett Syndrome ................................................................................................ 457
  Christopher C. Giza, Raman Sankar

Spina Bifida (SB) ............................................................................................ 460
  Christopher C. Giza, Raman Sankar
**Neuromuscular Disorders** ................................................................. 465
Muscular Dystrophies ................................................................. 465  
*Raman Sankar, Christopher C. Giza*

Myotonic Dystrophy ................................................................. 469  
*Raman Sankar, Christopher C. Giza*

Spinal Muscular Atrophy (SMA) .............................................. 472  
*Raman Sankar, Christopher C. Giza*

**Other Neurological Diseases** .................................................. 476
Adrenoleukodystrophy .............................................................. 476  
*Christopher C. Giza, Raman Sankar*

Friedreich Ataxia ................................................................. 479  
*Christopher C. Giza, Raman Sankar*

Moyamoya Syndrome ............................................................. 483  
*Christopher C. Giza, Raman Sankar*

Tic Disorder / Tourette Syndrome .......................................... 486  
*Christopher C. Giza, Raman Sankar*

**12 Oncologic Disorders** ............................................................ 491
Acute Lymphoblastic Leukemia (ALL) ......................................... 492  
*Pamela Kempert, Theodore B. Moore*

Acute Myelogenous Leukemia (AML) ......................................... 496  
*Pamela Kempert, Theodore B. Moore*

Ewing Family Tumors ............................................................. 500  
*Pamela Kempert, Theodore B. Moore*

Hodgkin Lymphoma ................................................................. 503  
*Pamela Kempert, Theodore B. Moore*

Medulloblastoma (MB) .............................................................. 507  
*Pamela Kempert, Theodore B. Moore*

Neuroblastoma ................................................................. 511  
*Pamela Kempert, Theodore B. Moore*

Non Hodgkin Lymphoma (NHL) .................................................. 515  
*Pamela Kempert, Theodore B. Moore*

Osteosarcoma (OS) ................................................................. 519  
*Pamela Kempert, Theodore B. Moore*

Pheochromocytoma ................................................................. 522  
*Pamela Kempert, Theodore B. Moore*

Rhabdomyosarcoma (RMS) .......................................................... 526  
*Pamela Kempert, Theodore B. Moore*

Wilms' Tumor (Nephroblastoma) .............................................. 529  
*Pamela Kempert, Theodore B. Moore*

Chemotherapy and Radiation Therapy ..................................... 533  
*Pamela Kempert, Theodore B. Moore*

**13 Pulmonary Disorders** ............................................................ 543
Chronic Lung Disease of Infancy (CLDi; Bronchopulmonary Dysplasia) ................................................................. 544  
*Roberta M. Kato, Thomas G. Keens*
14 Rheumatologic Disorders .................................................. 565

Behçets Disease ............................................................... 566
James N. Jarvis
Juvenile Dermatomyositis (JDM). ........................................ 569
James N. Jarvis
Familial Mediterranean Fever (FMF) ..................................... 572
James N. Jarvis
Juvenile Idiopathic Arthritis (JIA): Pauciarticular Subtype .... 574
James N. Jarvis
Juvenile Idiopathic Arthritis: Polyarticular Subtype ............. 577
James N. Jarvis
Systemic Onset Juvenile Idiopathic Arthritis (SoJIA). ......... 580
James N. Jarvis
Spondyloarthropathy ......................................................... 583
James N. Jarvis
Systemic Lupus Erythematosus (SLE) ............................... 586
James N. Jarvis

15 Medical Devices and Therapies ......................................... 589

Home Apnea Monitor ......................................................... 590
Sheila Kun
Dialysis ................................................................. 593
Katherine Wesseling Perry
Feeding Pumps ............................................................... 596
Laura J. Wozniak
Feeding Tubes ............................................................... 598
Laura J. Wozniak
Home Oxygen Therapy .................................................... 602
Sheila Kun
Insulin Pump Therapy ....................................................... 606
Eba H. Hathout
Home Nebulizer Therapy ................................................................. 609
  Sheila Kun

Ostomies ....................................................................................... 612
  Laura J. Wozniak, Linda M. Roof

Tracheostomy Tube for Children .................................................. 615
  Sheila Kun

Urinary Bladder Catheters .............................................................. 619
  Katherine Wesseling Perry

16 Disease Drug Interactions ......................................................... 621

  Asthma or Reactive Airway Disease ............................................ 622
    Wendy H.P. Ren, Samuel H. Wald

  Attention Deficit Hyperactivity Disorder .................................... 624
    Wendy H.P. Ren, Samuel H. Wald

  Epilepsy ....................................................................................... 627
    Wendy H.P. Ren, Samuel H. Wald

  Muscular Dystrophy ................................................................. 629
    Wendy H.P. Ren, Samuel H. Wald

  Myotonic Dystrophy ................................................................. 630
    Wendy H.P. Ren, Samuel H. Wald

  Pheochromocytoma .................................................................... 631
    Wendy H.P. Ren, Samuel H. Wald

  Porphyrias .................................................................................. 632
    Wendy H.P. Ren, Samuel H. Wald

  Upper Respiratory Tract Infection ............................................. 633
    Wendy H.P. Ren, Samuel H. Wald

  Herbal Substances’ Effect on Medications ................................... 634
    Wendy H.P. Ren, Samuel H. Wald

17 Transplant ................................................................................. 637

  Cardiac Transplantation ............................................................ 638
    Gary M. Satou, Thomas S. Klitzner

  End Stage Liver Disease (ESLD) & Pediatric Liver Transplantation (LTx) .......................................................... 642
    Robert S. Venick

  Lung Transplantation ............................................................... 646
    Roberta M. Kato, Thomas G. Keens

  Renal Transplantation ............................................................... 649
    Katherine Wesseling Perry

  Intestinal Failure and Intestinal Transplantation ......................... 652
    Robert S. Venick

  Pediatric Stem Cell Transplant (SCT) ........................................ 656
    Jerry C. Cheng, Theodore B. Moore
Tables

3.1: Complications Associated with Certain Hemangiomas ................................................................. 72
4.1: Presenting Endocrine Deficiencies at Time of Tumor Diagnosis ................................................... 86
5.1: Serologic Screens: Advantages and Disadvantages ............................................................................ 117
5.2: Options for Medical Treatment of Crohn’s Disease ........................................................... 131
5.3: Signs and Symptoms of Nutritional Problems .............................................................................. 155
5.4: Antibiotics Used in Small Bowel Bacterial Overgrowth .............................................................. 157
5.5: Options for Medical Treatment of Ulcerative colitis ...................................................................... 162
7.1: Red Cell Membrane Disorders ..................................................................................................... 224
7.2: Agents Producing Hemolysis in G-6-PD Deficiency ...................................................................... 228
7.3: Alpha Thalassemia States ............................................................................................................. 232
7.4: Symptoms of Methemoglobinemia ............................................................................................... 252
7.5: Inherited Pancytopenias ................................................................................................................. 253
7.6: Work-up of Patient with Aplastic Pancytopenia ........................................................................... 255
7.7: Treatment of Hemophilia ........................................................................................................... 260
7.8: Von Willebrand Disease .............................................................................................................. 266
7.9: Disorders of Platelet Function ...................................................................................................... 272
7.10: Laboratory Diagnosis of Platelet Function Disorders .................................................................. 274
7.11: Causes of Thrombophilia ............................................................................................................ 277
9.1: Different Phases of Hepatitis B ....................................................................................................... 318
9.2: Types and Phases of Hepatitis B .................................................................................................... 318
10.1: Signs and Symptoms of Bartter’s Syndrome ............................................................................... 340
10.2: Cysteamine (Cystagon) Dosage ................................................................................................... 350
11.1: Treatment and Dosages for Seizure Disorders .......................................................................... 392
11.2: Neuronal ceroid lipofuscinosis Clinical Presentations ................................................................ 418
11.3: Revised Diagnostic Criteria for Tuberous Sclerosis ................................................................. 439
11.4 Red Flags for Early Language Screening ..................................................................................... 453
12.1: Malignancy, Treatments and Toxicities Associated with Chemotherapy and Radiation ......... 535
16.1: Summary of Herbal Interactions .................................................................................................. 634
17.1: Post-allogeneic Transplant Complications ................................................................................... 658

Figures

7.1 View of The Typical Clotting Cascade ............................................................................................... 258
7.2: Diagnosing Anemia in Children .................................................................................................... 284
This book is dedicated to Marcy and Madison Smith who have inspired us, and the caring clinicians-educators who masterfully care for these children. We go forward with the notion that there is yet much to be done in understanding and caring for them.
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Recent advances in treatment of previously lethal pediatric illnesses has led to a growing population of children who require complex, chronic medical care. Most of this care is done at home or occasionally in chronic care facilities. Thus, the physicians including generalists, pediatricians and other health care personnel must provide acute and chronic care of these children in the office or emergency room setting.

This book was borne out of our own need for a concise, practical guide to assist in the care of children with complex diseases. This book focuses on the acute and long-term management of these children along with essential information regarding the pathogenesis, epidemiology, and prognosis of each disease. The diseases chosen for this book tend to be of a chronic, complex nature; require extensive specialized care; and lack readily accessible practice guidelines. Therefore, the authors have shared their knowledge and experience in order to assist primary care physicians better manage these illnesses. However, the more general chapters that focus on such issues as forming a medical home, management of medical devices, and disease drug interactions are relevant to the care of all children.

We thank all of our authors for their invaluable input and expertise and it is our hope that this guide book will assist physicians and other caretakers in improving the health and quality of life for these children and their families.

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Creating the Medical Home

Introduction

Children with special health care needs interact with and receive services from a myriad of complex systems, and their parents must learn to access, navigate and coordinate services related to health care, developmental disabilities, special education, mental health, insurers and more. In addition, families may face challenges related to language, culture, socioeconomic status, and the ongoing daily burden of caring for a child with a chronic health condition. A medical home is a practice model that can serve to assist families by providing high quality care for children that is comprehensive, family-centered and coordinated in nature.

The American Academy of Pediatrics (AAP) defines a medical home as “a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care.” In March 2007, the American Academy of Family Physicians (AAFP), the AAP, the American College of Physicians (ACP) and the American Osteopathic Association (AOA) published the Joint Principles of the Patient-Centered Medical Home, which defined the patient-centered medical home (PC-MH) as “an approach to providing comprehensive primary care for children, youth and adults. The PC-MH is a practice paradigm that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient’s family.”

Most medical home definitions make reference to primary care, and for most children, this care will be delivered by a primary care provider in the child’s community. But, for some—as is the case of children with rare or complex conditions—the specialist-, university-, or children’s hospital-based special care center may serve as the medical home. For children with chronic conditions, the medical home provides linkages to needed services and coordination of care, a central repository of information about the child, and a place for families to seek information and support. In addition, because the medical home provider knows the child well, parents and providers can work together as partners to assure that the needs of the child are met in a timely and efficient way. Literature suggests that the medical home can have a positive impact on both the individual child and family, and on the health care system, as emergency department use may be reduced. The medical home concept, by definition, improves coordination between primary and specialty care providers, and community based agencies and programs serving the child and family.
What Constitutes a Medical Home?

The joint position paper of the AAFP, AAP, ACP and AOA, describes the basic elements of the medical home to include the following:

- A personal physician for first contact, continuous, and comprehensive care.
- A physician-directed medical practice with a team of individuals to provide ongoing care.
- A whole person orientation in which the physician takes responsibility for providing or arranging for all of the patient’s acute, chronic, preventive or end of life care.
- Care that is coordinated and integrated across all components of the health care system.
- Assistance in transition to adult centered health care systems and supports.
- Quality and safety of care including advocacy, evidence based practices, continuous quality improvement, patient participation in decision making, the use of information technology, and participation in voluntary recognition processes.
- Enhanced access to care, expanded hours, and new options for communication with patients.
- Payment that appropriately recognizes the added value of the medical home.

Simply put, a medical home provides a base from which families can operate in caring for the child’s special health care needs. In addition to providing primary, preventive and episodic illness care, the medical home provider

- assists families in identifying needed services and supports,
- refers families to care providers as appropriate,
- coordinates the care between multiple providers,
- consolidates medical records in one location, and
- facilitates transitions between in- and outpatient-care; and from pediatric- to adult-oriented providers.

While the child’s care may be delivered in multiple locations by various types of providers, the medical home and the family work together to oversee the big picture, and understand how all the services and supports work together to provide comprehensive care for the child. This prevents gaps or duplications in services, and results in care that is comprehensive and cost effective. In short, optimal health care.

Benefits of Medical Home

Although serving as a medical home is a significant responsibility, there are several benefits to be derived both for the practice and the family. Foremost, families have one central and unifying health care environment for their child and an ongoing source of information and support. For providers, a medical home model encourages increased practice efficiencies and innovation, allows for easier patient follow up, and provides for shared patient care responsibility with specialists and community based services.

Families play an important role in the medical home and its members are considered full partners in their child’s care. While the primary care provider or specialist may be the expert in the health care needed by the child, the family is the overall expert in their child as a whole. They are the constant in the child’s life and provide the primary day-to-day care and support. In the medical home, families can be empowered to take a more proactive role in their child’s care. For instance, they can be encouraged to create care notebooks that can be used to organize their child’s records and facilitate communication among providers. The medical home is also a place where they can be provided with information about their child’s condition, services, and supports so that they can advocate more effectively on behalf of their child.
What Are the Goals of the Medical Home?

The aim of the medical home is to provide high quality health care that is family-centered and coordinated, and is a place where parents and providers work together to set goals, seek services, monitor care and advocate to achieve the best possible outcomes for the child. Goal setting is carried out collaboratively by the parent, child if appropriate, and physician, as well as other members of the care team. Goals should be realistic and achievable and may change as the child’s condition or family circumstances alter.

Several factors come into play in achieving those goals. First, comprehensive primary, preventive and episodic illness care is provided by a team led by a personal physician. Other team members may include nursing staff, care coordinators and/or administrative support staff within the practice setting. Next, the medical home is responsible for meeting the standards of basic pediatric health care for the child, and providing ongoing health education and support to the family. In addition, the medical home provides referrals to appropriate specialists as needed, and services in the community, such as special education and therapies. Third, families are given information about how and where to receive services, and what to expect. Lastly, the medical home provider maintains contact with the family to assure that referrals are successful and that the child ultimately receives needed services.

In a medical home, care is patient- and family-centered. Patient- and family-centered care is “grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.” The core concepts of patient- and family-centered care include:

1) **Dignity and respect**: In which the provider listens to and honors patient and family perspectives and choices and incorporates patient and family knowledge, values, beliefs and cultural backgrounds into the planning and delivery of care.

2) **Information sharing**: Where providers communicate and share complete and unbiased information with patients and families who receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

3) **Participation**: Where patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

4) **Collaboration**: In which patients and families are included in policy and program development, implementation, and evaluation, in health care facility design; and in professional education, as well as in the delivery of care (Institute for Family Centered Care, 2009). Providers and parents work as partners to identify child and family needs, and to locate and choose appropriate resources to meet those needs. This requires adequate time for communication with the family.

In order to optimize care and meet the family’s goals, patient and family-centered care should be practiced by all members of the medical home.

A primary responsibility of the medical home is care coordination and chronic care management. This includes coordination among specialist physicians, community based resources, and service systems such as special education or the developmental disabilities system. Care coordination is more than making a referral. It includes ensuring that the family understands the reason for other needed services; assisting the family to access care; and periodically reassessing the effectiveness of the service and adjusting care accordingly. The medical home provides information to the referral on the one hand; while on the other obtains information from the service provider; incorporates it into the medical record; and shares and interprets the information for the family.

It is impossible for an individual physician to provide all elements of care in the medical home, and an understanding of resources in the community, as well as relationships with specialty care providers can assist in meeting the needs of children and their families. Certain core resources including the Medicaid or CHIP
program, mental health services, the State title V program for Children with Special Needs, the developmental disabilities system, the early intervention system, special education, family resource centers, Head Start, and the Special Supplemental Food Program for Women, Infants and Children (WIC) are used by many families of children with special needs. Learning about these basic resources and how referrals are made to each can help the provider both meet the child and family’s needs and share responsibility for care with other programs, many of whom offer some form of care coordination or case management. Oftentimes, responsibility for learning about these entities can be delegated to support staff in the office who can then learn more about each and establish relationships upon which referrals can be built. Many of these programs also have outreach materials that can be kept in the provider’s office and shared with families when referrals are made.

Transforming a practice into a medical home takes time, with gradual and ongoing changes in practices, processes and shifts in philosophy of care. The transformation takes persistence and patience to achieve desired goals. Serving as a medical home requires regular self assessment to ensure that family needs are met, and that the practice setting is operating in a cost effective and efficient manner. There are a number of tools that exist to assist providers in self assessment, and to make simple changes to enhance the quality of care in a medical home practice. Likewise, there are now voluntary recognition programs to acknowledge the efforts of a medical home. It is likely that some of the current voluntary efforts will become mandatory as a means of assuring quality in compensating medical homes for care. Two examples of tools for self assessment include: (1) The Center for Medical Home Improvement’s Medical Home Index; and (2) the National Committee on Quality Assurance (NCQA) Physician Practice Connections- Patient Centered Medical Home program. The Medical Home Index measures the medical “homeness” of a practice across six domains including:

- organizational capacity;
- chronic condition management;
- care coordination;
- community outreach;
- data management; and
- quality improvement.

The NCQA program assesses whether physician practices are functioning as medical homes across nine standards, including:

- access and communication;
- patient tracking and registry;
- care management;
- patient self management support;
- electronic prescribing;
- test tracking, referral tracking;
- performance improvement; and
- advanced electronic communications.

Accumulating data increasingly supports the notion that the patient centered medical home for children with special health care needs can improve patient satisfaction while reducing inpatient hospital utilization and emergency room visits. For example, the Medical Home Program for Children with Special Health Care Needs is a medical home program in the resident continuity clinic at UCLA with a strong chronic care management component. When patient data was compared for one year prior to- and after-enrollment in the program, analysis of encounter data for patients enrolled in this program demonstrates a significant decrease in emergency room use. This finding is consistent with reports of other programs focused on populations of children with chronic disease. Thus, it is likely that parents of children with chronic conditions who are enrolled
in an active medical home are empowered to use telephone consultations or schedule outpatient appointments, and urgent care clinics to avoid emergency room visits. This hypothesis is supported by several parents reports in the UCLA Medical Home Program’s parent advisory group who gave this explanation when they were shown data on emergency room use and asked to comment. In addition, when compared to normative data for medical homes, we have found that the UCLA program results in much higher parent satisfaction scores as measured by the Medical Home Family Index which is a module of the Medical Home Index. Of note, the use of Spanish speaking Family Liaisons has resulted in high parent satisfaction scores among Spanish speaking families that are not significantly different from those of English speaking families.

A medical home is only valuable to patients and families if it is accessible. Accessibility constitutes a variety of factors. One factor is physical and includes structural accessibility for families who need additional space, ramps and elevators to move wheelchairs, ventilators and other equipment when bringing their child for a visit, or a larger than usual exam room in order to accommodate their needs, or a height adjustable exam table to be able to transfer a child with mobility impairments. Another factor is more temporal: Accessibility to providers at times that are convenient to families—such as late in the day and Saturdays—and access to other means of advice when the office is closed. Cultural and language accessibility is important in providing a medical home so that families can speak in their native language to their providers and that their culture is respected as part of the medical home processes. Finally, financial accessibility is a consideration, with the goal of access to a medical home regardless of the payer source.

A significant challenge for medical home providers is appropriate compensation. The activities that define a medical home take time, resources and appropriately trained staff. Currently, third party payers do not typically reimburse for the care coordination component of the medical home, but recent health reform proposals have identified the medical home model as an important means of ensuring access, enhancing care, and improving cost effectiveness. With heightened attention to the model, the possibility exists for recognizing the necessity of appropriate reimbursement.

Establishing a Medical Home

A variety of roles need to be filled in order to carry out the activities associated with a medical home. Primary care, acute/episodic illness care, and chronic disease management are key elements. While typically the pediatrician or family practitioner carries out these activities, nurse practitioners or physician assistants may play a role as well. Care coordination is a critical piece of the services provided in the medical home. While the physician may serve as the care coordinator in a smaller practice, this role is often assumed by a nurse, social worker, medical assistants, lay case managers, or specially trained parents in larger practices. Adequate training must assure that the care coordinator is knowledgeable about community resources and public programs that families may need to utilize. In addition, the care coordinator must have interpersonal skills that facilitate partnerships with families as well as providers, agencies and programs to which families are referred. They should have experience with the care coordination process of assessing family strengths and needs, identifying appropriate resources, referrals, follow up and evaluation and revising the plan as needed. Finally, they should have the ability to communicate with families in the family’s native language or through a medical translator.

Additional resources at the end of the chapter provide information and strategies for setting up a medical home, and practice management tools to enhance this effort. Some simple strategies; however, are virtually universal. It is helpful to identify the charts of those children with special health care needs. This allows the medical home practice to track the number of such children for purposes of resource allocation and arranging time-appropriate appointment setting allowing for additional time that these children often require.