Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care

November 5 - 6, 2009

Denton A. Cooley Auditorium
Texas Heart Institute
at St. Luke’s Episcopal Hospital
6720 Bertner Avenue
Green Elevators, Floor B1
Houston, Texas 77030

presented by
Baylor College of Medicine, Department of Pediatrics, and
Texas Children’s Hospital

The Maternal and Child Health Bureau-sponsored
Leadership Education in Adolescent Health (LEAH) Training Program

sponsored by
Baylor College of Medicine
Houston, Texas

Supported by a grant from Health Resources and Services Administration, Maternal and Child Health Bureau, grant #5T71 MC00011-13
OVERVIEW
The conference provides a state-of-the-art update on issues involved in transitioning youth and young adults with chronic illness and disability to adult-based services. In its tenth year, this conference has developed a singular reputation. It brings together nationally and locally-recognized clinical, policy, legal, research, advocacy, and family member experts, making it a unique conference by addressing all aspects of transition planning. This symposium is known for the highest quality presentations and exceptional dialogue among health care professionals, policy experts, young adults, and family members.

For clinicians, the conference includes discussions applicable to both primary and specialty care practices and provides an interdisciplinary perspective on how teams can facilitate the important transition from pediatric to adult-based healthcare. Topics will include the relationship between the medical home and subspecialists, planning for transition from the pediatric perspective, receiving patients in transition from the pediatric medicine perspective, and management of disease-specific conditions in transition at pediatric and adult hospitals.

For parents, teens, and young adults, the conference offers an opportunity to hear practical medical, legal, and insurance information. Conference presentations this year also cover important issues with respect to waivers programs, insurance, and education.

For clinicians, youth with special needs, and their families, the conference includes time to meet and talk with faculty, to exchange ideas among participants, including experienced clinicians, parents, and young adults, and to share knowledge and insight about how best to plan for a successful transition to adulthood.
NEEDS
Children with special health care needs (CSHCN) are those who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This population is significant in terms of its size and relationship to the U.S. health care system. One in five families has a child/youth with special health care needs. Understanding and addressing the gaps in access and quality of care for this population is an important national public health priority.

In addition, as a result of early detection of chronic conditions in children, advances in medical treatment strategies, and improved health systems, the vast majority of CSHCN will survive to adulthood. Based on estimates by the Center for Disease Control and Prevention, National Center for Health Statistics, roughly 500,000 youth with special health care needs (YSHCN) will turn 18 each year. Consequently, there is a growing need to focus on the well-being and health care access of these young adults and to provide/improve services in transitioning from pediatric to adult-based care.

Primary care providers, subspecialists, other professionals, and families caring for the increasing numbers of CSHCN and YSHCN often have inadequate support or knowledge of community resources. In addition, CSHCH and YSHCN often require the care of multiple specialists and primary care providers often have limited capacity to coordinate care. Interdisciplinary training about transition issues is needed for healthcare, education, public policy, and social service professionals.

TARGET AUDIENCE
• Physicians in the specialties of internal medicine, family practice, pediatrics, psychiatry, and physiatry
• Other healthcare professionals working with youth and young adults with chronic illness including psychologists, social workers, nurses, dieticians, case managers, counselors, and public health officials
• Primary care providers
• Youth and young adults with chronic illness and their parents/guardians

OBJECTIVES
At the conclusion of the activity, the participant should be able to:
• Differentiate between the transfer of care and the transition of care from pediatric to adult-based services for YSHCN.
• Describe how they will integrate transition-related discussions with patients with special health care needs and family members into their clinical practice.
• Identify the key components of the medical history that must be included in the transfer summary that the receiving physician has in his/her hands when seeing the transitioning patient for the first time.
• Describe the benefits of enhanced communication between physicians who care for YSHCN and identify practical approaches to improve communication.
• Discuss the impact of no health insurance coverage on the medical transition process with young adult patients with special health care needs and their families and to help identify resources available to address this crucial issue.

ACCREDITATION/CREDIT DESIGNATION
Baylor College of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Baylor College of Medicine designates this educational activity for a maximum of 13.25 AMA PRA Category 1 Credit(s)™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

The presentation, Legal Issues in Transition, has been designated by Baylor College of Medicine for .75 credits of education in medical ethics and/or professional responsibility.

Nurses
CNE contact hours available to nurses.

Texas Children’s Hospital is an approved provider of continuing nursing education by the Texas Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation.

Social Workers
This conference is pending approval for social work CEUs by the Graduate College of Social Work at the University of Houston. Once approved, it will be acceptable for Licensed Professional Counselors and Licensed Marriage and Family Therapists. All other disciplines should verify CEU acceptance with the licensing board.

Visit our website located at www.BaylorCME.org for information about Baylor College of Medicine CME activities.
PROGRAM SCHEDULE

THURSDAY, NOVEMBER 5, 2009

7:00 AM  Registration and Continental Breakfast

8:00     Welcome and Announcements
         Albert C. Hergenroeder, MD

         Film – Wheelchair Hip Hop, You Tube

8:15     Current Performance of Transition Services in the U.S. for Children and Youth with
         Special Healthcare Needs
         Bonnie Strickland, PhD

9:00     Transition From Pediatric to Adult-based Care in the U.S. – Bridging the Pediatric
         and Adult Medicine Cultures to Facilitate Transition Care
         Patience White, MD

9:45     Questions and Answers

10:00    Break

10:15    Preparing the Youth/Young Adult and Family for Transition:  What Youth and
         Families Need to Improve Transition Outcomes and How They Can Work to Get It
         Patti Hackett, MEd

11:00    Legal Issues in Transition
         Beth Sufian, JD

11:45    Questions and Answers

12:00 pm Boxed Lunch with Faculty Groups: (please select one below)
         Preparing for Transition (Hackett)
         Parents’ Perspective (Hime)
         Internal Medicine Perspective (Peacock)
         Evaluating Transitions’ Outcomes (Strickland)
         Preparing for Transition at a Children’s Hospital (White)

1:15     Breakout Session I with Faculty: Preparing For and Delivering Transition Services

1) Preparing Youth and Families for Transition: Clinical Interview During a
   Multidisciplinary Clinic Visit
   Diane Murrell, LMSW

2) Evaluation of Transition Outcome – How and What to Measure
   Bonnie Strickland, PhD

3) Starting a Transition Clinic in a Medicine-pediatrics Program
   Cynthia Peacock, MD

4) Starting a Transition Program in a Children’s Hospital
   Patience White, MD

5) A Parent’s Perspective on Successful Transition
   Patti Hackett, MEd

2:00     Breakout Session II with Faculty (repeat of session I)

2:45     Break

3:00     Financing Transition Services: State and Federal Perspectives
         Colleen Horton, MPAFF, and Bonnie Strickland, PhD

3:45     Questions and Answers

4:00     Adjourn
FRIDAY, NOVEMBER 6, 2009

7:30 am  Continental Breakfast and Sign In
8:00  Announcements and Award Announcement  
Albert C. Hergenroeder, MD
8:15  Youth/Young Adults’ Perspectives on Transition  
Michelle Colvard, MPH, Gary J. Lynn, Campsey Thomas
9:00  Questions and Answers
9:10  Family Members’ Perspectives on Transition  
Abby Hime, Linda Litzinger, Chava White, LMSW-AP, CCM
9:55  Questions and Answers
10:05  Break
10:15  Explanation of Waivers and Other Insurance Options  
Elizabeth Tucker
11:00  Questions and Answers
11:15  Pediatric Subspecialists and the Medical Home: Coordinating Care for CYSHCN  
Between Specialists and Primary Care Providers  
Jennifer L. Lail, MD
12:00 pm  Lunch  
Dionysus Theatre Performance

1:30 – 3:30  CONCURRENT SESSIONS-TRACK 1: MEDICAL  
Methods and Outcomes: Examples of Medically-oriented Transition Programs in Houston
1:30  Incorporating an Electronic Transition Template Into a Hospital-wide EMR: Preliminary Findings  
Albert C. Hergenroeder, MD
2:05  The Baylor Transition Clinic: Experience to Date, Plans for the Future  
Cynthia Peacock, MD
2:40  Break
2:55  Transition for Patients with Complex Congenital Health Disease: Lessons Learned and Next Steps  
Wayne J. Franklin, MD
3:30  Questions for the Medical Panel

1:30 – 3:30  CONCURRENT SESSIONS-TRACK 2: FAMILY  
Family and Youth Oriented Programs Based in Houston
1:30  The Transition Program at Shriner’s Hospital  
Ana Calvo, MSW
2:05  Region 4 Education Service Center  
Karen Pepkin
2:40  Break
2:55  DARS and Advocacy  
Karen Stanfill, CAP
3:30  Questions for the Family Panel
3:45  Wrap-up Remarks  
Albert C. Hergenroeder, MD
4:00  Adjourn

This CME activity is underwritten by an educational grant from Health Resource Services Administration, Maternal and Child Health Bureau, grant #5T71 MC00011-13.
**FACULTY**

**Ana Calvo, MSW**  
Transition Coordinator  
Shriners Hospital for Children  
Ms. Wheelchair Texas 2009  
Chair, City of Houston Commission for People with Disabilities  
Resident Cast Member, Dionysus Theater  
Houston, Texas

**Michelle Colvard, MPH**  
Ms. Wheelchair Texas 2008  
Ms. Wheelchair America 2009  
Houston, Texas

**Wayne J. Franklin, MD**  
Assistant Professor  
Department of Pediatrics – Cardiology  
Department of Medicine  
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Texas Children’s Hospital  
St. Luke’s Episcopal Hospital  
Director, Texas Adult Congenital Heart Center  
Houston, Texas

**Juanita Gonzalez**  
Area Work Incentive Coordinator  
Social Security Administration  
Houston, Texas

**Patti Hackett, MEd**  
Team Lead and Co-Director  
Healthy & Ready to Work National Resource Center  
Natick, Massachusetts

**Abby Hime**  
Houston, Texas

**Elaine Hime**  
Project Manager  
Project DOCC (Delivery of Chronic Care)  
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Houston, Texas

**Albert C. Hergenroeder, MD**  
Professor of Pediatrics  
Adolescent Medicine and Sports Medicine  
Baylor College of Medicine  
Project Director, BCM LEAH Program  
Chief, Adolescent Medicine Service  
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Houston, Texas

**Colleen Horton, MPAFF**  
Public Policy Director  
Texas Center for Disability Studies  
The University of Texas  
Austin, Texas

**Jennifer L. Lail, MD**  
Pediatrician  
Chapel Hill Pediatrics and Adolescents, PA  
Chapel Hill, North Carolina

**Linda Litzinger**  
Founder  
Texas Parent Advocates Consortium  
Austin, Texas

**Gary J. Lynn**  
Founder  
The Gary J. Lynn Foundation for the Research and Cure of Cerebral Palsy  
Houston, Texas

**Diane V. Murrell, LMSW**  
Social Worker  
Texas Children’s Hospital  
Houston, Texas

**Deb Nowinski**  
Artistic Director/Founder  
Dionysus Theatre  
Houston, Texas

**Kathleen Overdiep**  
Advocate  
Advocacy, Inc.  
Houston, Texas

**Cynthia Peacock, MD**  
Assistant Professor  
Baylor Transition Clinic Medical Director  
Baylor College of Medicine Combined Medicine – Pediatric Program Director  
Houston, Texas

**Karen L. Pepkin**  
Education Specialist  
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Houston, Texas

**Bonnie Strickland, PhD**  
Director  
Division of Services for CSHCN  
Rockville, Maryland

**Karen Stanfill, CAP**  
Client Assistance Program Coordinator  
Advocacy, Inc.  
Houston, Texas

**Beth Sufian, JD**  
Attorney and Director  
Cystic Fibrosis Legal Information Hotline  
Houston, Texas

**Campsey Thomas**  
Language Arts Teacher  
Houston Independent School District  
Houston, Texas

**Elizabeth Tucker**  
Director of Policy Development  
EveryChild, Inc.  
Austin, Texas

**Chava White, LMSW-AP, CCM**  
Advanced Practice Social Worker  
St. Luke’s Episcopal Hospital  
Houston, Texas

**Patience White, MD**  
Professor of Pediatrics and Medicine  
George Washington University  
Washington, DC
FEE, REGISTRATION AND CONFIRMATION INFORMATION

Refer to the registration form for the fee schedule. Your registration will not be processed until payment is received. Your registration will be confirmed. If you have not received confirmation at least 5 business days before the activity start date, contact the Office of Continuing Medical Education (OCME) immediately.

If you plan to register on-site, contact OCME at least 24 hours in advance to confirm activity status and space availability. The OCME reserves the right to limit the number of participants in an activity and will not be responsible for any expenses incurred by an individual whose registration is not confirmed and for whom space is not available.

To register/pay online, visit the activity website at www.BaylorCME.org/CME/1424 and follow the instructions.

CANCELLATION/REFUND POLICY

Requests for registration refunds must be in writing and received by the Office of Continuing Medical Education (OCME) at least 10 business days before the activity begins. The date the request is received by the OCME will be considered the cancellation date. Requests received after the refund deadline will not be processed. Cancellations are subject to a $50 administrative fee deducted from the registration fee paid to cover guarantees and other expenses. Requests should be mailed to the OCME or faxed to 713.798.7955.

The OCME reserves the right to cancel activities, not less than 10 business days before the scheduled date, if extenuating circumstances make it necessary. Registrants will be notified at the contact number indicated on the registration form followed by written notification. If an activity is cancelled, OCME’s liability is limited to the registration fee paid. Note: If payment is made by check, a social security number is required to process a refund.

CONFERENCE ACCOMMODATIONS

Marriott Medical Center Hotel
6580 Fannin Street
Houston, Texas 77030
Phone: 713.796.0080 or 800.228.9290
Fax: 713.796.8100

Accommodations should be arranged directly with the Marriott Medical Center Hotel. Please identify yourself with the Baylor College of Medicine Chronic Illness Conference when making reservations in order to benefit from the special group rate ($114.00 single/double). Rooms have been reserved at the special rate on a space available basis. The deadline to receive the special rate is October 14, 2009, unless the room block has already been filled. Reserve your room early.

FOR FURTHER INFORMATION CONTACT

Baylor College of Medicine
Office of Continuing Medical Education
One Baylor Plaza, MS: BCM 155
Houston, Texas 77030
Phone: 713.798.8237
Fax: 713.798.7955

Visit our website located at www.BaylorCME.org for information about Baylor College of Medicine CME activities.

In order to meet the requirements of the Accreditation Council for Continuing Medical Education it is the policy of Baylor College of Medicine that all individuals who are in a position to control the content of a CME activity (activity director, planning committee members, and faculty) disclose relevant financial relationships with commercial interests. All identified conflicts of interest are managed to help ensure that the educational material is scientifically based, accurate, and objectively presented. Specific disclosure will be made to the participants prior to the educational activity.

Faculty, topics, program schedule, and credit are subject to change.

Audio or videotaping is prohibited without written permission from the Activity Director and the Office of Continuing Medical Education, Baylor College of Medicine, Houston, Texas.
Note: Marriott Medical Center Hotel provides free shuttle service. Notify valet at least 15 minutes in advance that you want a ride to St. Luke’s Episcopal Hospital. Enter building and follow signs to Green Elevators; take Green Elevators to Level B1. Call the Marriott at 713.796.0080 for return shuttle to hotel.
ANNOUNCES THE 10TH ANNUAL

Chronic Illness and Disability:
*Transition from Pediatric to Adult-Based Care*

REGISTRATION FORM

November 5 – 6, 2009
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Houston, Texas 77030

Please print

Name ___________________________ Degree ___________________________
Affiliation ___________________________
Address ___________________________
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Office ___________________________ Phone ___________________________
Fax ___________________________
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(for activity-related follow-up, e.g., outcomes assessment)

Specialty ___________________________
Professional License No./State ___________________________

Emergency Contact Name ___________________________
Phone ___________________________

PAYMENT METHOD (specify)

☐ CHECK (in U.S. Funds) made payable to Baylor College of Medicine
☐ CREDIT CARD ☐ VISA® ☐ MasterCard® ☐ DISCOVER® ☐ AMEX®

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Return completed registration form and payment to:

Baylor College of Medicine
Office of Continuing Medical Education (1424)
P.O. Box 4708
Houston, Texas 77210-4708

With credit card payment, you may fax completed registration form to 713.798.7955.

REGISTRATION FEE (please indicate category)

Physician ☐ $250.00
Nurse ☐ $150.00
Social Worker ☐ $150.00
Other ☐ $150.00
Youth/Family Member ☐ $75.00
BCM Faculty* ☐ $125.00
BCM Resident* ☐ $100.00
BCM Fellow* ☐ $100.00
BCM Student* ☐ $100.00

*Verification of status must accompany registration form. Fax to 713.798.7955

This low registration fee would not be possible without the generous support of Health Resources and Services Administration, Maternal and Child Health Bureau.

Special Dietary Needs (specify) ___________________________
Contact OCME if you have any ADA accommodation needs.