13th CHRONIC ILLNESS AND DISABILITY CONFERENCE

### **Transition from Pediatric to Adult-based Care**





Thursday October 18<sup>th</sup> and Friday October 19<sup>th</sup>, 2012

MD Anderson Cancer Center Mitchell Basic Science Research Building 6767 Bertner Avenue Onstead Auditorium, 3rd Floor Houston, TX 77030

RETURNING THIS YEAR!

Healthcare Transition Research Consortium Research Day Wednesday October 17, 2012

11:00 A.M. - 5:30 P.M. (Details on page 5)





#### PLANNING COMMITTEE

#### Albert C. Hergenroeder, MD-Activity Director

Valerie F. Bowman, LMSW | Rebecca Carman, MSW | Marylee Dilling, MD Hilary Griffin, BBA | Kathy Griffis-Bailey, MS | Elaine Hime, BS | Marie Mann, MD Diane Murrell, LCSW | Rebecca J. Schultz, PhD, RN | Sherry Sellers - Vinson, MD Shelley Townsend | Chava White, LMSW-AP, CCM | David L. Wood, MD, MPH

#### **ACTIVITY FACULTY**

#### Valerie F. Bowman, LMSW

Project Manager Adolescent Medicine and Sports Medicine Baylor College of Medicine Houston, Texas

#### Deborah L. Brown, MD

Assistant Professor of Pediatrics
The University of Texas Medical School
at Houston
Gulf States Hemophilia
and Thrombophilia Center
Houston, Texas

#### Angelo P. Giardino, MD, PhD

Vice President Texas Children's Hospital Health Plan Houston, Texas

#### Kathy Griffis-Bailey, MS

Title V CSHCN Services Program
Department of State Health Services
Austin, Texas

#### Albert C. Hergenroeder, MD

Professor of Pediatrics Adolescent Medicine and Sports Medicine Baylor College of Medicine Chief, Adolescent Medicine Service Texas Children's Hospital Houston, Texas

#### Elaine Hime, BS

Project Manager Project Delivery of Chronic Care (DOCC) Texas Children's Hospital Houston, Texas

#### John G. Reiss, PhD

Associate Professor
Institute for Child Health Policy
University of Florida
Gainesville, Florida

#### Peter B. Scal, MD, MPH

Assistant Professor Academic General Pediatrics University of Minnesota Minneapolis, Minnesota

#### Rebecca J. Schultz, PhD, RN

Assistant Professor of Pediatrics Texas Children's Hospital Houston, Texas

#### Beth Sufian, JD

Attorney and Director Cystic Fibrosis Legal Information Hotline Houston, Texas

#### L. Vance Taylor

Principal Catalyst Partners, LLC Washington, DC

#### Brad Thompson, MS, LPC

Director, The HALI Project, Inc. Amarillo, Texas

#### Mark Wallace

President and CEO Texas Children's Hospital Houston, Texas

#### Patience H. White, MD, MA

Chief Public Health Officer National Arthritis Foundation Washington, DC

#### David L. Wood, MD, MPH

Professor of Pediatrics University of Florida College of Medicine Jacksonville, Florida

#### **CONFERENCE OVERVIEW**

Skill preparation and planning for healthcare transition for children and youth with special healthcare needs (CYSHCN) and their families is inadequate. Less than 50% of families nationwide indicate that their CYSHCN have received the services necessary to make appropriate transitions to adult healthcare, work, and independence. One of the major problems to receiving this care is the lack of a physician workforce trained in providing the services necessary to make the healthcare transition. This conference provides a state-of-the-art update on issues involved in healthcare transition for youth and young adults with chronic illness and disability and their families from pediatric to adult-based services.

Now in its 13th year, the conference brings together internationally, nationally, and locally recognized clinical, policy, legal, research, advocacy, and family experts. Addressing all aspects of transition planning, this conference strengthens the dialogue among healthcare professionals, policy experts, youth and young adults, and family members. For clinicians, the conference includes discussions applicable to both primary and specialty care practice and provides an interdisciplinary perspective on how teams can facilitate the important transition from pediatric to adult-based healthcare. For policy and advocacy experts, the conference provides updates on recent developments. For researchers, it updates recent findings. For parents, teens, and young adults, the conference offers an opportunity to hear practical medical, legal, and insurance information. For all audience members there will be a discussion of the legal issues involved in healthcare insurance during healthcare transition; as well as time to meet and talk with faculty, to exchange ideas among participants, and to share knowledge and insight about how best to plan for a successful transition to adulthood.

#### TARGET AUDIENCE

Physicians in internal medicine, family practice, pediatrics, psychiatry, and physiatry; other healthcare providers including, psychologists, social workers, nurses, dietitians, 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 conference, participants should be able to:

- Develop methods to transition pediatric patients with special healthcare needs to adult-based care.
- Identify strategies to strengthen collaborative healthcare transition planning between children and young adults with special healthcare needs, parents/guardians, and providers.
- Identify strategies to improve communication between pediatric and adult healthcare providers of children and young adults with special healthcare needs
- Discuss the key features of the new Affordable Care Act and options for medical insurance for young adults with disabilities.
- Screen children and young adults with special health care needs for neurocognitive deficits and determine appropriate follow up to maximize outcomes.
- Assess the needs of the family as well as the child or young adult with special healthcare needs, with referrals to appropriate community-based services.

#### **EDUCATIONAL METHODS**

Lecture ■ Question and Answer Sessions ■ Panel Discussion

#### **EVALUATION**

Evaluation by questionnaire will address program content, presentation, and possible bias.

#### 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 live activity for a maximum of 12.75 *AMA PRA Category 1 Credits*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

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 Work continuing education units (11.5 hours, including one hour in ethics) for this conference have been approved by the Department of Case Management and Social Work at Texas Children's Hospital.

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

#### DISCLOSURE POLICY

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.

#### FEE, REGISTRATION, AND CONFIRMATION INFORMATION

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

A limited number of scholarships are available for CYSHCN and their parents/guardians. Please contact Valerie Bowman at <a href="mailto:TRACS@texaschildrens.org">TRACS@texaschildrens.org</a> for complete details.

If you plan to register on-site, contact the 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 <u>BaylorCME.org/CME/1463</u> and follow the instructions.

#### CANCELLATION/REFUND POLICY

Requests for registration refunds must be in writing and received by the 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 the refund.

# Healthcare Transition Research Consortium RESEARCH DAY

WEDNESDAY, OCTOBER 17, 2012 ■ 11:00 A.M. - 5:30 P.M.

MD Anderson Cancer Center | Mitchell Basic Science Research Building 6767 Bertner Avenue
Onstead Auditorium, 3rd Floor
Houston, TX 77030

#### **OVERVIEW**

A research-oriented panel composed of parents, youth and emerging adults that speaks to their unique issues and concerns in collaboration with interdisciplinary health researchers. Topics will include challenges to participating in research studies, experience with participatory action research, and research problems/questions of interest to parents and consumers.

#### REGISTRATION

There is no cost to attend Research Day, however, registration is required. Please complete the registration form or register online to confirm your attendance.

#### **AGENDA**

#### 11:00 AM

Poster exhibit opens, authors are present at their posters. Lunch on your own.

#### Noon - 12:30 PM WELCOME REMARKS

Maria E. Ferris, MD, MPH, PhD Associate Professor of Pediatrics and Medicine University of North Carolina at Chapel Hill

David L. Wood, MD, MPH
Professor of Pediatrics
University of Florida, College of Medicine

#### 12:30 - 1:30

Research Panel with Question and Answer Session

1:30 - 2:30

Oral Presentation of Selected Posters

2:30 - 2:45 BREAK

2:45 - 3:45

Research Panel with Question and Answer Session

3:45 - 4:45

Research Panel with Question and Answer Session

4:45 - 5:30

Closing Comments and Adjourn

NOTE: HCTRC Research Day is not designated for physician, nursing, or social work credit.

## Agenda

#### THURSDAY ■ OCTOBER 18, 2012

7:00 ам	Registration and Continental Breakfast				
8:00	Welcome and Announcements Albert C. Hergenroeder, MD				
	Film Presentation: Nick Vujicic—"No Arms, No Legs, No Worries'				
8:15	Health Care Transition at Texas Children's Hospital Mark Wallace, President and CEO of Texas Children's Hospital				
8:30	The Current State of Health Care Transition in the U.S. <i>Patience H. White, MD, MA</i>				
9:15	Building a State Health Care Transition Plan David L. Wood, MD, MPH and John G. Reiss, PhD				
10:00	Question and Answer Session				
10:15	Break				
10:30	HEADSSS-Up for Transition: Transition as an Adolescent Health Promotion Clinical Activity Peter B. Scal, MD, MPH				
11:15	Legal Issues in Transition Beth Sufian, JD				
12:00 рм	Question and Answer Session				
12:15	BOXED LUNCH WITH FACULTY GROUPS (select one):				
	Parent Advocacy-Brad Thompson, MS, LPC				
	Parents as Case Managers-Elaine Hime, BS				
	Building a Clinical Transition Program–Patience H. White, MD, MA				
	Building Statewide Transition Coalitions—David L. Wood, MD, MPH and John G. Reiss, PhD				
	Legal Issues–Beth Sufian, JD				
	Youth and Young Adults with Neurocognitive Disabilities— Peter B. Scal, MD, MPH				

### BREAKOUT SESSION ONE WITH FACULTY: *Preparing for and Delivering Transition Services*

(Please choose one; sessions will repeat at 2:00 PM).

1:15 Health Care Transition for Adolescent and Young Adults with Neurodevelopmental Conditions

Peter B. Scal, MD, MPH

The Adult Provider's Perspective on Health Care Transition – Practical Aspects

Patience H. White, MD, MA

A Parent's Perspective on Successful Advocacy for Health Care Transition

Brad Thompson, MS, LPC and Elaine Hime, BS

**Building a Financial Model for Health Care Transition** *Angelo P. Giardino, MD, PhD* 

Understanding the Texas Title V Program for CYSHCN Kathy Griffis-Bailey, MS

Implementing a Transition Planning Tool into an Electronic Medical Record

Valerie F. Bowman, LMSW

#### BREAKOUT SESSION TWO WITH FACULTY

2:00	Repeat of Session 1 topics. See previous page.
2:45	Break
3:00	$ \begin{array}{l} \textbf{Transition for Youth and Young Adults with Hemophilia} \\ \textit{Deborah L. Brown, MD} \end{array} $
3:45	Question and Answer Session
4:00	Adjourn

# Agenda

#### FRIDAY ■ OCTOBER 19, 2012

7:30 ам	Registration and Continental Breakfast			
8:00	Announcements Albert C. Hergenroeder, MD			
8:15	Youth/Young Adults' Perspectives on Transition Albert C. Hergenroeder, MD and L. Vance Taylor			
9:00	Question and Answer Session			
9:10	Young Adult Perspective L. Vance Taylor			
9:55	Question and Answer Session			
10:05	Break			
10:15	Family Members' Perspectives on Transition Brad Thompson, MS, LPC and Elaine Hime, BS			
11:00	Question and Answer Session			
11:15	Considerations in Health Care Transition from a Nursing Perspective Rebecca J. Schultz, PhD, RN			
12:00 рм	Question and Answer Session			
12:05	Lunch			
1:00	Financing Transition Services: State and Federal Perspective Angelo P. Giardino, MD, PhD			
1:45	Break			
2:00	HRSA-funded "An Innovative Model for Facilitating Adult Services Through Transition (AIM-FAST)" Albert C. Hergenroeder, MD			
2:15	The Best of the Research Presentations from Research Day: Got Transition and the Health Care Transition Research Consortium			
3:00	Quality Improvement in Health Care Transition: Applying the Principles of Quality Improvement to Health Care Transition Angelo P. Giardino, MD, PhD			
3:45	Question and Answer Session			
4:00	Closing Comments			
4:15	Adjourn			

Faculty, topics, program schedule, and credit are subject to change. Audio or videotaping is prohibited without written permission from the Activity Director and the OCME, Baylor College of Medicine, Houston, Texas.

#### **CONFERENCE LOCATION**

#### MD Anderson Cancer Center ■ Mitchell Basic Science Research Building

6767 Bertner Avenue Onstead Auditorium, 3rd Floor Houston, TX 77030

Parking is available in the McGovern Commons parking garage. Unfortunately we are unable to validate parking. Parking is \$12/day. Onstead Auditorium may be accessed from the McGovern Commons Building through the first floor breezeway.

If you are staying at the Houston Marriott at the Texas Medical Center hotel, a complimentary shuttle is available. Please notify the hotel valet at least 15 minutes in advance for transportation to Onstead Auditorium.



You may wish to bring a sweater or light jacket as the temperature in the auditorium can vary.

#### **ACCOMMODATIONS**

Houston Marriott at the Texas Medical Center 6580 Fannin Street | Houston, TX 77030 713.796.0080

Accommodations should be arranged directly with the Houston Marriott at the Texas Medical Center by calling 800.228.9290. Please identify yourself with the *Baylor College of Medicine Transition Conference* when making reservations in order to benefit from the special group rate (\$155 Single/Double, plus tax). A limited number of rooms will be available and have been reserved at the special rate on a space available basis. *The deadline to receive the special rate is Tuesday, September 25, 2012, unless the room block has already been filled.* 

#### FOR FURTHER INFORMATION CONTACT

Baylor College of Medicine Phone: 713.798.8237
Office of CME Fax: 713.798.7955
One Baylor Plaza, MS: BCM155 Email: cme@bcm.edu

Houston, TX 77030

Visit our website, <u>BaylorCME.org</u> for information regarding upcoming Baylor College of Medicine CME activities.

#### 13th CHRONIC ILLNESS AND DISABILITY CONFERENCE

# Transition from Pediatric to Adult-based Care

Thursday-Friday ■ October 18-19, 2012

(Please print	clearly)		iliuisuay-riiday	Jelubel 16-19, 2012	
Name:					
Degree:				🗆 Resident 🚨 Fellow	
Affiliation: _					
Address:					
City:			State:	Zip:	
Phone:			Fax:		
Email:					
Specialty:					
Professional	License (No./S	State):			
Emergency (	Contact/Phone	No.:			
REGISTRATI	ON FEES				
Physician Nurse			BCM Faculty Member Fellow, Resident, Medical Stu	\$150 dent* \$100	
Social Worker			outh, Family Member	\$100	
Other Healthcar	re Professional		Fax verification status within 24 hrs. of	registration.	
RESEARCH I	DAY (OCTOBER	17th) 🗆 Yes, I	will attend. 🔲 No, I w	ill not attend.	
OCTOBER 18	Bth BREAKOUT S		hese sessions repeat at 2:00 p		
1:15 p.m.	2:00 p.m.	ıs	session below for 1:15 p.m. and	ONE Session for 2:00 p.m.	
☐ Session 1A	☐ Session 2A	Health Care Transition for Adolescent and Young Adults with Neurodevelopmental Conditions			
☐ Session 1B	☐ Session 2B	The Adult Provider's Perspective on Health Care Transition-Practical Aspects			
☐ Session 1C	☐ Session 2C	A Parent's Perspective on Successful Advocacy for Health Care Transition			
☐ Session 1D	☐ Session 2D	_	Model for Health Care Transit		
☐ Session 1E	☐ Session 2E		exas Title V Program for CYSH		
☐ Session 1F	☐ Session 2F	Implementing a Transition Planning Tool into an Electronic Medical Record			
Method of	Payment (Yo	our registration m	ust be PREPAID)		
☐ Check or	money order (	in U.S. funds) mad	le payable to: Baylor Co	ollege of Medicine	
□ Visa® □	MasterCard®	☐ Discover® ☐ A	Amex® \$Tot	al Amount Enclosed	
Card No			Ехр	o. Date:	
Authorized S	Signature:				
	card payment, y	you may fax 1 to 713.798.7955.	Special I	Requests	
•			Contact OCME if you have	any dietary needs (specify	
Return completed form and payment to: Baylor College of Medicine Office of CME (1463), P.O. Box 4708 Houston, Texas 77210-4708				commodation needs.	
This low registratio	n fee would not be po	ssible without the generous	s support of Health		

Resources and Services Administration, Maternal and Child Health Bureau.

To register/pay online, visit the activity website at <a href="mailto:BaylorCME.org/CME/1463"><u>BaylorCME.org/CME/1463</u></a> and follow the instructions.

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CK CC LB Cash
Date:

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