

**24<sup>th</sup> Annual**  
**Chronic Illness and Disability Conference:**  
***Transition from Pediatric to Adult-Based Care***

**OCTOBER 26-27, 2023**

*Resuming the in-person meeting format  
for the first time since 2019*



*Co-provided by:*



## PLANNING COMMITTEE

**Albert C. Hergenroeder, MD – Activity Director**

Cecily L. Betz, PhD, RN, FAAN  
Jackie Czyzia, MPH  
Scott Garner, MBA  
Ivy Goldstein  
Cynda Green

Laura Hardy, MBA  
Albert C. Hergenroeder, MD  
Elaine Hime  
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Peggy McManus, MHS

Rachel Miller  
Diane Murrell, LMSW  
Shelley Townsend, MSW  
Chava White, LMSW-AP  
Audrey Young, MPH

## ACTIVITY FACULTY

All faculty are located in Houston, Texas, unless otherwise noted.

### **William Anderson, MD**

Associate Professor, Pediatric Allergy & Immunology,  
Director, Multidisciplinary Asthma Clinic, Co-  
Director, CHICO Improving Pediatric to  
Adult Care Transition (ImPACT) Program,  
Children's Hospital Colorado  
Denver, CO

### **Michelle Colvard, MPH**

Director, Research Administration,  
University of Texas MD Anderson Cancer Center

### **Lynn F. Davidson, MD, FAAP**

Associate Professor of Pediatrics,  
Division of Academic General Pediatrics,  
Children's Hospital, Albert Einstein College of Medicine  
Bronx, NY

### **Ellen Fremion, MD, FAAP, FACP**

Associate Professor of Internal Medicine and Pediatrics,  
Baylor Transition Medicine Clinic,  
Clinical Director at the Center for Pursuit,  
Texas Children's Hospital Spina Bifida Transition  
Clinic Director

### **Angelo Giardino, MD, PhD**

Chair, Department of Pediatrics,  
University of Utah's School of Medicine,  
Chief Medical Officer,  
Intermountain Primary Children's Hospital  
Salt Lake City, UT

### **Peter Hotez, MD, PhD, DSc (hon), FASTMH, FAAP**

Dean, National School of Tropical Medicine,  
Professor, Departments of Pediatrics,  
Molecular Virology & Microbiology;  
Endowed Chair of Tropical Pediatrics/Co-director,  
Texas Children's Hospital Center for Vaccine Development

### **Raghuveer Puttagunta, MD**

Associate Chief Medical Informatics Officer,  
Hospitalist, Internal Medicine – Pediatrics,  
Pediatric Complex Care Clinic/Comprehensive Care Clinic,  
Geisinger Health System  
Danville, PA

### **David Robinson**

Member, Houston City Counsel and/or  
Director City of Houston Health Department

### **Jane N.T. Sattoe, PhD**

Senior Researcher,  
Research Centre Innovations in Care,  
Rotterdam University of Applied Sciences  
Rotterdam, The Netherlands

### **Drew and Kelly Scoggins**

Owners of Houston's Bitty and Beau's Coffee Shop

### **Beth Sufian, JD**

Partner, Sufian & Passamano

### **Peggy Turner, BS, CTRS**

Athletics Community Liaison,  
Adapted Sports & Recreation Community Programs  
Coordinator, Texas Institute for Rehabilitation and Research  
(TIRR) Memorial Hermann

## NEEDS STATEMENT

Skill preparation and planning for healthcare transition for children and youth with special healthcare needs is inadequate. Less than fifty percent of families nationwide indicate that their children with special healthcare needs have received the services necessary to make appropriate transitions to adult healthcare, work, and independence. One of the major hurdles to receiving this care is the lack of a workforce, including physicians, nurses, social workers, mental health providers and all who provide services to youth and young adults with special healthcare needs trained to provide the services necessary to make the healthcare transition. There is a strong need for physicians to have the knowledge and skills to provide the services needed to facilitate a successful transition from pediatric to adult-based care and services.

Because of increased awareness of transitioning to adult-based care, clinicians are required to update their knowledge of the changing strategies for integrating emerging adult-based care into practice.

For all conference participants, there will be a discussion of the legal issues involved in healthcare transition, as well as time to meet and talk with faculty in small groups, to exchange ideas among participants, and to share knowledge and information 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 primary care providers; and youth and young adults who have a chronic illness or disability and their parents or guardians.

## LEARNING OBJECTIVES

At the conclusion of the conference, participants should be able to:

- Describe the legal and ethical issues involved in HCT for adolescents and young adults with special health care needs (AYASHCN)
- Discuss the evidence for using interventions to promote self-management in AYASHCN
- Discuss the current state of EMR-based transition planning tools
- Discuss the importance and evidence for improving self-management for AYASHCN during transition
- Be able to implement person-centered and patient activating techniques in the provider-patient clinical visit
- Incorporate the patient and parent perspectives into health care transition programs
- Discuss issues in information transfer and confidentiality in the process of transitioning patients from pediatric to adult-based care and the impact of the 21st Century Cures Act
- Be able to incorporate techniques to improve HCT for AYASHCN with IDD
- Discuss establishing a transition planning program in a primary care practice

## EDUCATIONAL METHODS

Lectures • Small Group Breakout Sessions • Question and Answer Sessions • Audience Response System

## ACTIVITY EVALUATION

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

## ACCREDITATION/CREDIT DESIGNATION

### *Physicians*

Baylor College of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

Baylor College of Medicine designates this live activity for a maximum of 11.50 *AMA PRA Category 1 Credits*<sup>™</sup>. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

The presentation, *Legal Issues in the Transition from Pediatric to Adult-Based Care*, has been designated by Baylor College of Medicine for 1.0 credit of education in medical ethics and/or professional responsibility.

### ***Social Work***

Texas Children's Hospital is an approved continuing education provider for Social Workers through the Texas State Board of Social Worker Examiners. Social work continuing education units provided, 11.5 hours of continuing education including 1.0 hour of ethics.

### ***Nursing***

Texas Children's Hospital is accredited with distinction as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation. This continuing nursing education activity awards up to 11.5 contact hours.

This includes 1.0 out of the 2.0 contact hours required for Nursing Jurisprudence and Ethics Continuing Nursing Education Requirement.

### ***Occupational Therapy and Physical Therapy***

This activity has been approved by the Texas Board of Physical Therapy Examiners for 11.5 CCUs for PTs and PTAs.

Continuing Competency Units (CCU) have been applied for this conference through Texas Occupational Therapy Association (TOTA) 11.5 hours credit. Texas Children's Hospital is an Approved Provider for the Texas Occupational Therapy Association. The assignment of TOTA CE hours does not imply endorsement of a specific course, content, products, or clinical procedures by TOTA.

## **FEE, REGISTRATION AND CONFIRMATION INFORMATION**

Refer to the online registration form at [cpd.education.bcm.edu/content/chronic2023](http://cpd.education.bcm.edu/content/chronic2023) 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 Baylor College of Medicine (BCM) Division of Continuing Professional Development (DCPD) immediately.

A limited number of scholarships are available for adolescents and young adults with special health care needs and their parents or guardians. For complete details, please contact Cynda Green at [cynda.green@txp2p.org](mailto:cynda.green@txp2p.org).

The DCPD 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 for the conference, visit our website at [cpd.education.bcm.edu/content/chronic2023](http://cpd.education.bcm.edu/content/chronic2023).

## **CANCELLATION/REFUND POLICY**

Requests for registration refunds must be in writing and received by the DCPD at least 10 business days before the activity begins. The date the request is received by the DCPD will be considered the cancellation date. Requests received after the refund deadline will not be processed. Cancellations are subject to a \$50 administrative fee to be deducted from the paid registration fee to cover guarantees and other expenses. Requests should be emailed to [cpd@bcm.edu](mailto:cpd@bcm.edu).

The DCPD 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 and again in writing. If an activity is canceled, the DCPD's liability is limited to the paid registration fee. Note: If the registration payment was made by check, a Social Security number is required to process the refund.



# 24<sup>th</sup> Annual Chronic Illness and Disability Conference:

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

### AGENDA

**THURSDAY, OCTOBER 26, 2023**

7:15 a.m. Registration, coffee and bagels in the lobby

8:00 **Welcome and Announcements**

**Albert C. Hergenroeder, MD**

8:15 **Inspirational Video: TBD**

8:25 **Houston City Council Proclamation**

**David Robinson**, Houston City Council at-Large

8:35 **Self-Management Interventions:**

**What is the evidence base?**

**Jane N.T. Sattoe, PhD**

Senior Researcher, Research Centre Innovations in Care,  
Rotterdam University of Applied Sciences  
Rotterdam, The Netherlands

Goal: The audience will be able to understand the importance of self-management in successful transition.

Objectives: The audience will be able to describe:

- The relationship between self-management and health care transition outcomes
- The components of self-management
- The measurement of self-management
- Evidence of interventions to improve self-management

9:20 **Building EMR-based Transition Planning Tools:**

**Overview**

**William Anderson, MD**

Associate Professor, Pediatric Allergy & Immunology,  
Director, Multidisciplinary Asthma Clinic, Co-Director,  
CHICO Improving Pediatric to Adult Care Transition  
(ImPACT) Program, Children's Hospital Colorado  
Denver, CO

Goal: The audience will be able to understand the current state of EMR-based transition planning tools.

Objectives: The audience will be able to describe:

- The current state of the use of EMR-based transition planning tools
- The evidence base for using transition planning tools in HCT
- Barriers to and successes in the use of transition planning tools in clinical practice

10:00 Q&A

10:15 Break

10:30 **Issues in Information Transfer and Confidentiality in the Process of Transition**

**Raghuveer Puttagunta, MD**

Associate Chief Medical Informatics Officer, Hospitalist,  
Internal Medicine – Pediatrics, Pediatric Complex Care  
Clinic/Comprehensive Care Clinic, Geisinger Health System  
Danville, PA

Goal: The audience would be able to talk about the various methods through which HIPPA-protected information is transferred from pediatric to adult-based care institutions.

Objectives: The audience will be able to discuss, with respect to information transfer between pediatric and adult institutions at the time of transition:

- Best practices
- The effect of the 21st Century Cures Act
- Barriers
- Confidentiality

11:15 **Legal Issues in the Transition From Pediatric to Adult-Based Care**

**Beth Sufian, JD**

Partner, Sufian & Passamano

Goal: The audience will be able to understand the significance of the Social Security Continuing Review Process and the impact of medical records on eligibility.

Objectives: The audience will be able to discuss:

- Government benefit changes that occur at the time of the health care transition in the context of the current eligibility review landscape.
- Social Security Continuing Disability Reviews and ensuring eligible individuals continue benefits.
- Health insurance options when certain coverage is lost due to age.

Noon Q&A

12:15 p.m. **Meet-the-Faculty Luncheon**

- Beth Sufian, JD
- Raghu Puttagunta, MD
- William Anderson, MD
- Got Transition
- TBD
- TBD

1:15 Conclusion of Luncheon sessions

1:35 **BREAKOUT SESSION I, WITH FACULTY**  
*Attendees please select one at 1:35 p.m. and a different one at 2:35 p.m.*

### Transition for Young Adults with Intellectual/Developmental Disabilities (YIADD)

**Elen Fremion, MD, FAAP, FACP**

Associate Professor of Internal Medicine and Pediatrics,  
Baylor Transition Medicine Clinic,  
Clinical Director at the Center for Pursuit,  
Texas Children's Hospital Spina Bifida Transition  
Clinic Director

Goal: The audience would be able to talk about state of transition care for YIADD nationally.

Objectives: The audience will be able to describe:

- The state of transition care for YIADD in the U.S
- Evidence-based guidelines for care for YIADD in transition.

### Legal Issues

**Beth Sufian, JD**

Partner, Sufian & Passamano

Goal: The audience will be able to understand guardianship and power of attorney and SSI non-eligibility as a teenager transitions into adulthood.

Objectives: The audience will be able to discuss:

- Guardianship decisions
- Insurance options

### Issues in Information Transfer and Confidentiality in the Process of Transition – Operational Issues

**Raghuv eer Puttagunta, MD**

Associate Chief Medical Informatics Officer, Hospitalist,  
Internal Medicine – Pediatrics, Pediatric Complex Care Clinic/  
Comprehensive Care Clinic, Geisinger Health System  
Danville, PA

Goal: The audience will understand unanticipated consequences and potential remedies.

Objectives: The audience will be able to describe:

- Operational issues in managing the transfer of information.
- Structure and processes of transition planning in the speaker's institution.

### Building the Transition Planning Tool (TPT) 2.0

**William Anderson, MD**

Associate Professor, Pediatric Allergy & Immunology,  
Director, Multidisciplinary Asthma Clinic,  
Co-Director, CHICO Improving Pediatric to Adult Care  
Transition (ImPACT) Program,  
Children's Hospital Colorado  
Denver, CO

Goal: The audience will be able to understand the current state of the Transition Planning Tool 2.0 in Epic at Denver Children's Hospital.

Objectives: The audience will be able to describe, with respect to the TPT 2.0.

- What gaps it was designed to fill
- How it was built and implemented
- Data on its use so far

### Employment for Young Adults with IDD

**Drew and Kelly Scoggins**

Owners of Houston's Bitty and Beau's Coffee Shop

Goal: The audience will understand the importance of employment for a young adult with chronic illness or disability from a parent and young adult's perspective.

Objectives: The audience will be able to describe:

- The structure and processes of the Bitty and Beau's Coffee shop in Houston
- What the speakers have learned in the process of setting up this employment opportunity
- The national perspective on employment opportunities for young adults with intellectual disabilities in the U.S
- Success stories from the employees at the coffee shop

### Methods of Promoting Self-management at the Patient-provider Level

**Jane N.T. Sattoe, PhD**

Senior Researcher, Research Centre Innovations in Care,  
Rotterdam University of Applied Sciences  
Rotterdam, The Netherlands

Goal: The audience will be able to understand methods to promote active involvement of the patient during the patient-provider encounter.

Objectives: The audience will be able to discuss:

- Adopting a person-centered approach
- Motivational interviewing techniques to promote

2:35 p.m. **BREAKOUT SESSION II, WITH FACULTY**  
*Attendees please select one at 1:35 p.m. and a different one at 2:35 p.m.*

3:20 Break

### 3:40 Transition in Primary Care

**Lynn F. Davidson, MD, FAAP**

Associate Professor of Pediatrics,  
Division of Academic General Pediatrics, Children's Hospital,  
Albert Einstein College of Medicine  
Bronx, NY

Goal: The audience will understand the importance of transition planning in primary care.

Objectives: The audience will be able implement strategies to:

- Establish the structure and processes of a transition planning program in a primary care setting
- Discuss information transfer techniques from pediatric to adult-based primary care

4:20 Q&A

4:30 Evaluation and Adjournment

## AGENDA

**FRIDAY, OCTOBER 27, 2023**

7:15 a.m. Registration, coffee and bagels in the lobby

8:00 **Announcements**

**Albert C. Hergenroeder, MD**

8:15 **How to Become a Batman**

**Michelle Colvard**

Director, Research Administration,  
University of Texas MD Anderson Research Center

Goal: The audience will understand medical, personal and professional transition from the perspective of an adult with a chronic disability who is now a parent.

Objective: The audience will be able to describe:

- Challenges with youth and young adults with disabilities during transition to adulthood and adult based care
- Challenges from a parent's in supporting normal child development

9:00 Q&A

9:10 **Parental Perspective: Transitioning a Daughter With Autism**

**Peter Hotez, MD, PhD, DSc (hon), FASTMH, FAAP**

Dean, National School of Tropical Medicine,  
Professor, Departments of Pediatrics,  
Molecular Virology & Microbiology;  
Endowed Chair of Tropical Pediatrics/Co-director,  
Texas Children's Hospital Center for Vaccine Development

Goal: The audience will understand the speaker's challenges the speaker, his wife and daughter have encountered in transitioning her care to the adult health care system.

Objectives: The audience will be able to describe barriers in transition related to:

- Insurance
- Finding a provider
- Home care
- Mental health issues
- How the speaker incorporated autism into his professional development

9:40 Q&A

9:55 Break

10:05 **Dental Care**

**TBD**

Goal: The audience will understand the challenges for delivering dental care to adolescents and young adults with special health care needs.

Objectives: The audience will be able to describe:

- The dental needs of youth and young adults with special health care needs in the U.S
- The special needs of those with intellectual, developmental and emotional disabilities
- Barriers to receiving dental care during the transition years (18-25)
- Programs to deliver this care and train the next workforce of dental providers

10:50 **Financing HCT**

**Angelo Giardino, MD, PhD**

Chair, Department of Pediatrics,  
University of Utah's School of Medicine,  
Chief Medical Officer Intermountain Primary  
Children's Hospital  
Salt Lake City, UT

Goal: The audience would be able to understand the complexity of financing health care transition and how it applies to their health care setting.

Objectives: The audience would be able to discuss, in the context of financing health care transition from pediatric to adult-based care (HCT):

- Value-based care
- Managed care
- Structural elements to payments (e.g. contractual language)
- Process outcomes in a successful HCT payment plan
- A model of a successful payment program in HCT

11:35 Q&A

11:45 Lunch

1:00 p.m. **Adaptive Sports**

**Peggy Turner, BS, CTRS**

Athletics Community Liaison, Adapted Sports & Recreation  
Community Programs Coordinator,  
TIRR Memorial Hermann

Goal: The audience will be have a framework for establishing  
an adaptive sports program in their institution.

Objectives: The audience will be able to describe:

- The history of how the speaker's program was established
- The structure and processes of the current program
- Other adaptive sports programs

1:45 Q&A

1:55 Break

2:05 **The Transition Program at Children's Hospital  
Colorado**

**William Anderson, MD**

Associate Professor, Pediatric Allergy & Immunology,  
Director, Multidisciplinary Asthma Clinic,  
Co-Director, CHICO Improving Pediatric to Adult Care  
Transition (ImPACT) Program,  
Children's Hospital Colorado,  
Denver, CO

Goal: The audience will understand the transition program  
at Children's Hospital Colorado.

Objectives: The audience will be able to describe:

- The timeline in developing this program
- The structure and processes of the clinic
- Outcomes
- Lessons learned

2:45 **Improved Health Care Transition for Young Adults  
with Developmental at Texas Children's Hospital**

**Elen Fremion, MD, FAAP, FACP**

Associate Professor of Internal Medicine and Pediatrics,  
Baylor Transition Medicine Clinic,  
Clinical Director at the Center for Pursuit,  
Texas Children's Hospital Spina Bifida Transition  
Clinic Director

Goal: audience would be able to talk about the structure,  
processes and outcomes of the clinic serving young adults  
with intellectual disabilities (YAIDD) and potentially be able  
to apply some of these structure and processes to improve  
outcomes at their institution.

Objectives: The audience will be able to describe:

- The state of transition for YAIDD in the U.S
- Evidence-based guidelines for care for YAIDD in transition
- The structure and processes for the clinic
- Outcome data

3:30 Q&A

3:40 Closing Comments/Evaluation