

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

**October 24-25, 2019**



Co-provided by:



# PLANNING COMMITTEE

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

- Amanda K. Garey, MSN, RNC-OB, C-EFM
- Scott H. Garner, MBA
- Elaine J. Hime
- Benjamin Kaufman, MSW
- Siripoom McKay, MD
- Peggy McManus, MHS
- Diane V. Murrell, LMSW
- Katrine Nordstrom, MEd
- Rebecca J. Schultz, PhD, RN
- Shelley Townsend, MSW
- Sherry Sellers Vinson, MD
- Chava White, LMSW – AP
- Audrey Young, MPH

# ACTIVITY FACULTY

## **Miranda Banks**

Trainee and Sibling  
LoneStar LEND  
Houston, TX

## **John Berens, MD**

Assistant Professor  
Transition Medicine  
Baylor College of Medicine  
Houston, TX

## **Mary R. Ciccarelli, MD**

Professor of Clinical Medicine and Pediatrics  
Indiana University School of Medicine  
Indianapolis, IN

## **Eyal Cohen, MD, MSc, FRCP(C)**

Staff Physician, Co-Founder, Complex Care Program  
Paediatrics  
The Hospital for Sick Children  
Toronto, ON

## **Olivia Flagor**

Senior RN/BSN Nursing Student  
Texas Woman's University  
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## **Albert C. Hergenroeder, MD**

Professor of Pediatrics  
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## **Sophia Jan, MD**

Pediatrics, Internal Medicine  
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New Hyde Park, NY

## **Brendan Lee, MD, PhD**

Robert and Janice McNair Endowed Chair  
Molecular and Human Genetics  
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## **Gabriella Machin**

Parent Teacher for Project DOCC  
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## **Chaya Murali, MD**

Department of Molecular and Human Genetics  
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## **Diane Murrell, LMSW**

Social Worker  
Texas Children's Hospital  
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## **Robin Rayburn**

## **Beth Sufian, JD**

Partner  
Sufian & Passamano  
Houston, TX

## **Maria Town**

President and CEO  
American Association of People with Disabilities  
Washington, DC

## **Lee Wallace, EdD, RDN, LDN, FADA, FAND**

Chief of Nutrition  
The Boling Center for Developmental Disabilities  
The University of Tennessee Health Science Center  
Memphis, TN

## **Mary Williams**

Executive Director  
Family to Family Network  
Houston, TX

## CONFERENCE OVERVIEW

Skill preparation and planning for health care transition for children and youth with special health care needs is inadequate. Less than 50 percent of families nationwide indicate that their children with special health care needs have received the services necessary to make appropriate transitions to adult health care, 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 health care needs trained to provide the services necessary to make the health care 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 health care 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 health care 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.

## OBJECTIVES

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

- Describe strategies for setting up and evaluating a transition program
- Describe models of care for transitioning youth with medical complexity
- Discuss the current state of HCT from pediatric to adult based care
- Describe the non-medical aspects of care, such as formal planning related to HCT for families of AYASHCN
- Describe the legal issues associated with transition from pediatric to adult-based care

## EDUCATIONAL METHODS

Lecture ■ Meet the Faculty Sessions ■ Breakout Sessions ■ Question and Answer Sessions

## EVALUATION

A questionnaire will be used to evaluate and address program content, presentation, and possible bias.

## DISCLOSURE POLICY

To meet the requirements of the Accreditation Council for Continuing Medical Education (ACCME), it is the policy of Baylor College of Medicine that all individuals who are in a position to control the content of the 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, current, and objectively presented. Specific disclosure will be made to the participants before the educational activity.

Registration for, attendance at, and/or participation in this activity constitutes acknowledgment by the registrant/attendee/participant that photos may be made of the conference events and constitute agreement by the registrant/attendee/participant that Baylor College of Medicine may use and distribute in its publications, on its website, and in the conference proceedings, such photos that include the image of the registrant/attendee/participant.

By participating in the activity, the registrant/attendee/participant acknowledges that he/she agrees to these stipulations. 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.

## 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 14.00 *AMA PRA Category I Credits*<sup>™</sup>. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

The presentation, *Legal Issues in Health care Transition*, has been designated by Baylor College of Medicine for 1.0 credit of education in medical ethics and/or professional responsibility.

### Nursing

Texas Children's Hospital is an approved provider with commendation of continuing nursing education by the Texas Nurses Association – Approver, an accredited approver with distinction, by the American Nurses Credentialing Center's Commission on Accreditation.

### 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, 14 hours of continuing education including 1 hour of ethics.

### Occupational Therapy and Physical Therapy

Contact hours (CCUs) have been applied for through TPTA and TOTA. 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 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.

A limited number of scholarships are available for CYSHCN and their parents or guardians. For complete details, please contact Katrine Nordstrom at [Katrine.Nordstrom@txp2p.org](mailto:Katrine.Nordstrom@txp2p.org).

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 for the conference only, visit our website at [BaylorCME.org/CME/1623](http://BaylorCME.org/CME/1623) 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 to be deducted from the paid registration fee to cover guarantees and other expenses. Requests should be emailed to [cme@bcm.edu](mailto:cme@bcm.edu) 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 and again in writing. If an activity is cancelled, the OCME'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.

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

## AGENDA

THURSDAY, OCTOBER 24, 2019

- 7:00 a.m. **Registration and Continental Breakfast**
- 8:00 a.m. **Welcome and Announcements**  
Albert C. Hergenroeder, MD  
Professor of Pediatrics  
Chief, Adolescent Medicine & Sports Medicine  
Baylor College of Medicine  
Chief, Adolescent Medicine Service  
Texas Children's Hospital
- 8:15 a.m. **Observations of the Field of Health Care Transition and the Transition Conference over 20 years**  
Albert Hergenroeder, MD
- 8:45 a.m. **The Current State of Health Care Transition from Pediatric to Adult-Based Care**  
Mary Ciccarelli, MD  
Professor of Clinical Medicine and Pediatrics  
Indiana University School of Medicine
- 9:30 a.m. **Legal Issues in the Transition from Pediatric to Adult-Based Care**  
Beth Sufian, JD  
Partner  
Sufian & Passamano
- 10:15 a.m. **Questions and Answers**
- 10:30 a.m. Break
- 10:45 a.m. **Policies that Promote Employment Outcomes for Young Adults with Disabilities**  
Maria Town  
President & CEO  
American Association of People with Disabilities
- 11:30 a.m. **Questions and Answers**
- 11:45 a.m. Lunch
- 12:00 p.m. **Meet the Faculty**  
Diane Murrell, Maria Town, Eyal Cohen, Chaya Murali, Sophie Jan, John Berens, Parent Session
- 1:15 p.m. **Breakout Sessions I with Faculty:**
- 1) Building a Business to Serve Young Adults with Special Health Care Needs**  
Diane Murrell, LMSW  
Social Worker  
Texas Children's Hospital  
(panel of three business models that serve the disabled community with employment)
- 2) Policy development**  
Maria Town  
President & CEO  
American Association of People with Disabilities
- 3) Broadcast #1 – Measurement Matters: Transition Program Evaluation**  
Eyal Cohen, MD, MSc, FRCP(C)  
Staff Physician, Co-Founder, Complex Care Program  
Paediatrics  
The Hospital for Sick Children Toronto
- 4) Broadcast #2 – Writing Workshop**  
Chaya Murali, MD  
Department of Molecular & Human Genetics  
Baylor College of Medicine
- 5) Long-Term Care Options for Family Caregivers of those with IDD**  
Sophie Jan, MD  
Pediatrics, Internal Medicine  
Northwell Health
- John Berens, MD  
Assistant Professor, Transition Medicine  
Baylor College of Medicine
- 6) Parent Session**
- 2:15 p.m. **Breakout Sessions II with Faculty**
- 3:00 p.m. Break
- 3:15 p.m. **Nutritional Issues during Transition**  
Lee Shelly Wallace, EdD, RDN, LDN, FADA, FAND  
Chief of Nutrition, Coordinator of Inborn Errors of Metabolism Team, Boling Center for Developmental Disabilities  
University of Tennessee Health Science Center
- 4:00 p.m. **Questions and Answers**
- 4:00 p.m. **Evaluation**
- 4:10 p.m. **Adjourn**

Faculty, topics, and the symposium schedule are subject to change.

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

## AGENDA

FRIDAY, OCTOBER 25, 2019

7:30 a.m.	<b>Announcements</b> Albert C. Hergenroeder, MD Professor of Pediatrics Chief, Adolescent Medicine & Sports Medicine Baylor College of Medicine Chief, Adolescent Medicine Service Texas Children's Hospital	1:45 p.m.	Break
		2:00 p.m.	<b>Clinical Pathway – Developing a Standardized Approach to Transition Across Services at a Large Children's Hospital</b> Sophie Jan, MD Pediatrics, Internal Medicine Northwell Health
8:15 a.m.	<b>New Therapeutics in Pediatric Metabolic, Bone &amp; Other Rare Diseases</b> Brendan Lee, MD, PhD Robert & Janice McNair Endowed Chair in Molecular and Human Genetics Baylor College of Medicine	2:45 p.m.	<b>A Successful Transition Program</b> Diane Murrell, LMSW Social Worker Texas Children's Hospital
9:05 a.m.	<b>Questions and Answers</b>	3:30 p.m.	<b>Questions and Answers</b>
9:20 a.m.	<b>Young Adult Perspective</b> Ana Calvo, MSW Program Director of Transition Service Houston Community College	3:45 p.m.	<b>Evaluation</b>
		4:00 p.m.	<b>Closing Comments</b>
10:20 a.m.	<b>Questions and Answers</b>		
10:35 a.m.	Break		
10:50 a.m.	<b>Siblings' Perspective on Transition</b> Miranda Banks Trainee and Sibling LoneStar LEND  Olivia Flagor Senior RN/BSN Nursing Student Texas Woman's University		
11:30 a.m.	<b>Questions and Answers</b>		
11:45 a.m.	Lunch		
1:00 p.m.	<b>Transitioning Successful Models of Pediatric Complex Care into Adulthood</b> Eyal Cohen, MD, MSc, FRCP(C) Staff Physician, Co-Founder, Complex Care Program Paediatrics The Hospital for Sick Children Toronto		

## CONFERENCE LOCATION

MD Anderson Cancer Center ■ Mitchell Basic Sciences 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 1st floor breezeway.

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

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



## ACCOMMODATIONS

Houston Marriott Medical Center/Museum District  
1730 Dryden Road  
Houston, Texas 77030  
713.796.0080

Accommodations should be arranged directly with the Houston Marriott Medical Center/Museum District by calling 713.796.0080 or 800.228.9290. or go online (link below). Please identify yourself as an attendee of the 20th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care when making reservations to benefit from the special group rate of \$159 (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 Monday, September 30, 2019, unless the room block has already been filled.

### Houston Marriott Medical Center/Museum District registration:

<https://www.marriott.com/events/start.mi?id=1560264703934&key=GRP>

## FOR ADDITIONAL INFORMATION CONTACT

Araceli Romero	Phone: 832-824-1731
Texas Children's Hospital	Fax: 832-826-4253
6651 Main Street	Email: <a href="mailto:axromero@texaschildrens.org">axromero@texaschildrens.org</a>
Houston, Texas 77030	

Visit, [BaylorCME.org](http://BaylorCME.org) for information about upcoming Baylor College of Medicine CME programs and activities.

# REGISTRATION

20<sup>th</sup> Annual Chronic Illness and Disability Conference  
October 24-25, 2019

ONLINE: Research Symposium: [BaylorCME.org/CME/I623R](http://BaylorCME.org/CME/I623R)  
Transition Conference: [BaylorCME.org/CME/I623](http://BaylorCME.org/CME/I623)

MAIL: Baylor College of Medicine  
Office of CME (1623)  
P.O. Box 4708 | Houston, TX 77210-4708

(Please print clearly)

Name: \_\_\_\_\_  
Degree: \_\_\_\_\_  Resident  Fellow  Student  
Affiliation: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP Code: \_\_\_\_\_  
Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_  
Email: \_\_\_\_\_  
Specialty: \_\_\_\_\_ Prof. License: \_\_\_\_\_  
National Provider Identifier (NPI): \_\_\_\_\_  
Emergency Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

## YOU MUST REGISTER FOR EACH CONFERENCE SEPARATELY AT THE CORRESPONDING WEBSITE BELOW

### RESEARCH SYMPOSIUM ■ OCTOBER 23

Register online: [BaylorCME.org/CME/I623R](http://BaylorCME.org/CME/I623R)

REGISTRATION \$100 (All participants)

Yes, I will attend.  
 No, I will not attend.

Registration waiver available for students. Contact: Megumi J. Okumura, M.D., M.A.S. • [Megumi.Okumura@ucsf.edu](mailto:Megumi.Okumura@ucsf.edu)

### CONFERENCE ■ OCTOBER 24-25

Register online: [BaylorCME.org/CME/I623](http://BaylorCME.org/CME/I623)

#### REGISTRATION FEES (\*Fax verification status within 24 hours of registration to 713.798.7955.)

Physician .....\$350  BCM Faculty Member .....\$175  Youth .....\$125  
 Nurse .....\$225  Student\* .....\$50  Family Member/ Caregiver .....\$125  
 Social Worker .....\$225  Fellow\* .....\$50  
 Other Health care Professional .....\$225  Resident\* .....\$50

#### OCTOBER 24 MEET THE FACULTY LUNCH • Please select **ONE** from below:

Diane Murrell, LMSW  Chaya Murali, MD  Parent Session  
 Maria Town  Sophie Jan, MD  
 Eyal Cohen, MD, MSc, FRCP(C)  John Berens, MD.

#### OCTOBER 24 BREAKOUT SESSIONS • Please select **ONE** session for 1:15 p.m. and **ONE** session for 2:15 p.m

**1:15 PM** **2:15 PM.**  
 Session 1A  Session 2A Building a Business to Serve Young Adults with Special Health Care Needs  
 Session 1B  Session 2B Policy development  
 Session 1C  Session 2C Broadcast #1 – Measurement Matters: Transition Program Evaluation  
 Session 1D  Session 2D Broadcast #2 – Writing Workshop  
 Session 1E  Session 2E Long-Term Care Options for Family Caregivers of those with IDD  
 Session 1F  Session 2F Parent Session

#### METHOD OF PAYMENT FOR ALL (Your entire registration must be PREPAID.)

Check or money order (in U.S. funds) made payable to: Baylor College of Medicine  
 Visa®  MasterCard®  Discover®  Amex® \$ \_\_\_\_\_ Total Amount Enclosed  
Card No. \_\_\_\_\_ Exp. Date: \_\_\_\_\_  
Name on the Card: \_\_\_\_\_  
Authorized Signature: \_\_\_\_\_

**Special Requests:** Contact OCME if you have any dietary needs (specify below) or any ADA accommodation needs.

FOR OFFICIAL USE ONLY

CK CC LB Cash  
Date:  
Amount: