

# Preparing for the Next Chapter: *Empowerment for the Transition from Pediatric to Adult HTC Care*

PRESENTED BY:

KATHALEEN SCHNUR, MSW, LCSW AND MEREDITH GETZ, MSW, LSW

PANEL PARTICIPANTS: DYANNE MORRIS, BSN, RN AND DR. FREDERICO XAVIER, MS,  
MD – CLINICAL DIRECTOR OF PEDIATRIC SERVICES

# Introduction

- ▶ **Kathaleen Schnur, MSW, LCSW** – Social Worker with the Western PA HTC in Pittsburgh
- ▶ **Meredith Getz, MSW, LSW** – Social Worker with the HTC at Penn State Health Hershey Medical Center
- ▶ **Dr. Frederico Xavier, MD** – Pediatric Hematologist and Clinical Director of Pediatric Services with the Western PA HTC
- ▶ **Dyanne Morris, BSN, RN** – Nurse with the Penn Medicine HTC in Philadelphia

# Pennsylvania HTC

- ▶ 7 HTCs in Pennsylvania:
  - ▶ The Hemophilia Center of Western PA (Pittsburgh)
  - ▶ The Hemophilia Treatment of Central PA (Hershey)
  - ▶ Children's Hospital of Philadelphia (CHOP)
  - ▶ Cardeza Foundation Hemophilia Center (Philadelphia)
  - ▶ Lehigh Valley Hospital - Muhlenberg (Bethlehem)
  - ▶ Penn Comprehensive Hemophilia and Thrombosis Program (Philadelphia)
  - ▶ St. Christopher's Hospital for Children (Philadelphia)
- ▶ Pediatric care, adult care, and/or lifespan clinics
- ▶ Variability of services offered and care provided
- ▶ Hospital connection or stand alone HTCs

# Presentation Focus

- ▶ Taking a proactive approach to empower families, adolescents, teens, and young adults to build independence and readiness, facilitating a smooth, confident transition from pediatric to adult HTC care.
- ▶ Highlighting the importance of early preparation and the collaborative roles of healthcare providers, parents/caregivers, and patients, while addressing common barriers and challenges seen by adult providers during the transition to adult care.
- ▶ Identifying key challenges during the transition phase—including developing patient autonomy, fostering responsible health behaviors, and strengthening self-management skills.





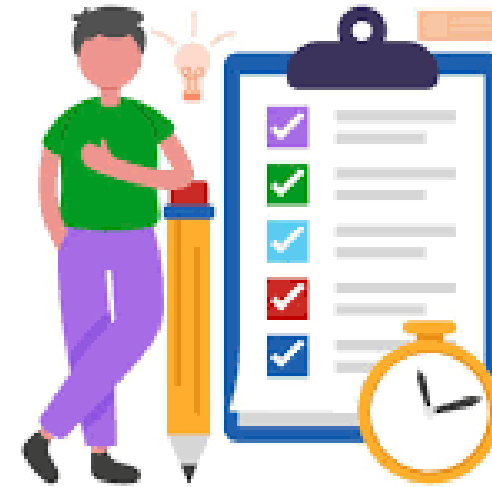
# Question to your HTC...

**At what age does your HTC staff begin working with families and caregivers to assess and prepare for transition readiness?**



# Self-Managing Care

- ▶ Teaching young adults to manage their treatment independently
- ▶ Understanding how to order medications, schedule appointments and coordinate their care
- ▶ What motivates your young adult to be independent?
- ▶ What goals can the patient create to empower their independence?



# Question to your HTC...

What are some of the key challenges you observe in preparing your pediatric patients and their families for the transition to adult care?



# Building Autonomy and Independence

- ▶ What is the role of the patient in managing their own care?
  - ▶ Moving from a passive to active role
  - ▶ “Bite-sized” steps in the transition
  - ▶ Highlighting patient strengths
  - ▶ This process is multiple conversations over time
  - ▶ Slowly adding more responsibilities to the patient to gain confidence
  - ▶ Setting the patient up for success
- ▶ Developing decision-making skills to be able to manage medication schedules, understand treatment options and access care.
- ▶ Discuss patient resistance to independence
- ▶ Foster self-advocacy



# Question to your HTC...

What are some of the challenges you observe in adults transitioning from pediatric to adult care?



# Shared Decision Making in Adult Care

- ▶ The importance of shared decision-making between the patient and their care team
- ▶ Encouraging active participation in treatment decisions and care planning
- ▶ Building trust and communication with new adult care providers



YOU (the patient) are the leader of the team!

# Community Involvement and Social Support

- ▶ The value of staying connected with the bleeding disorders community
- ▶ Accessing peer support groups, advocacy organizations, and mentorship opportunities
- ▶ Maintaining a balance between health care and social life: managing expectations and responsibilities



# Preparing for a Successful Transition

- ▶ Start early, move slowly, and take bite-sized pieces ☺
- ▶ Foster independence through empowerment, self-advocacy and informed decision-making
- ▶ Obtain practical resources and tools to support the transition process
- ▶ Encouraging continued communication between health care teams, patients and their families/caregivers



# Panel Q&A



# Thank you!

- ▶ Make sure to connect with your HTC for further guidance and support
- ▶ Maintain connection to your HTC for the most optimal health outcome with your bleeding disorder care needs

***Thank you for your participation in this presentation and we appreciate your attendance to the PA Bleeding Disorders Conference!***