



Keep in Touch and Stay on Track with your HTC

PRESENTED BY:

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PANEL PARTICIPANTS: BREE KELLY, BSN, RN AND DR. PETER CYGAN, MD

Introduction

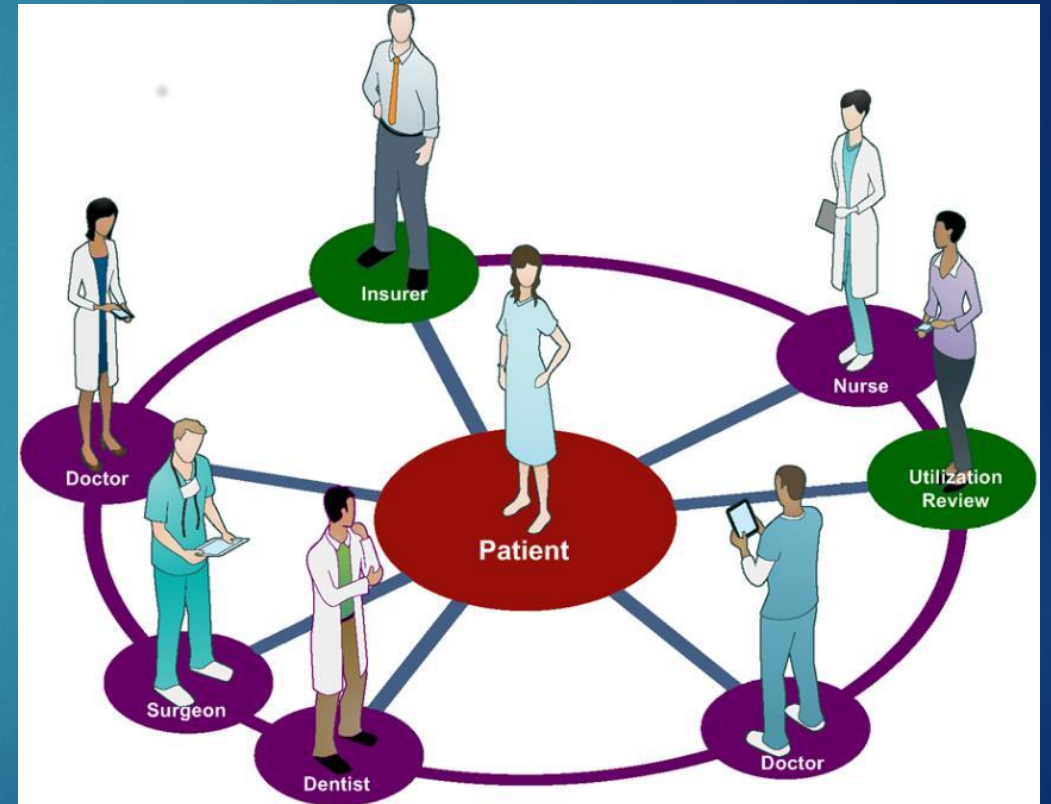
- ▶ **Kathaleen Schnur, MSW, LCSW** – Social Worker with the Western PA HTC in Pittsburgh
- ▶ **Meredith Getz, MSW, LSW** – Social Worker with the HTC at Penn State Health Hershey Medical Center
- ▶ **Bree Kelly, BSN, RN** – Nurse and Clinical Program Manager with the HTC at Penn State Health Hershey Medical Center
- ▶ **Dr. Peter Cygan, MD** – Hematologist with the HTC at Penn State Health Hershey Medical Center

Pennsylvania HTC's

- ▶ 7 HTC's 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 HTC's

HTC – Multidisciplinary Approach

- ▶ Patient = Team leader
- ▶ Multidisciplinary team members:
 - ▶ Hematologist
 - ▶ Nurse
 - ▶ Social Worker
 - ▶ Physical Therapist
- ▶ Some HTCs provide other services such as:
 - ▶ Genetic counselor
 - ▶ Infectious disease providers
 - ▶ Hepatology
 - ▶ Laboratory services
 - ▶ Educational/vocational counselor... etc.!



Panel Question

How does the HTC communicate with other providers about my bleeding disorder?



Understanding your Treatment Plan

- ▶ Importance of keeping on track of your treatments (injections/infusions)
- ▶ Monitoring your symptoms
- ▶ HTC can provide education and resources for self-management
- ▶ Keeping up to date with research and new medications that could improve your care
- ▶ Reviewing educational materials, clinic summaries, etc.

Communication

- ▶ Each HTC has their own directions for their patients/families on when to reach out
- ▶ The key is open-lines of communication!
- ▶ Reasons to call:
 - ▶ Injury, treatment, procedures, changes in insurance, contact information updates, etc.
- ▶ Questions that might be asked:
 - ▶ Injury = Mechanism of fall, situation, time, area of the body injured, treatments completed, evaluate for ED visit
 - ▶ Procedure = Location, type, contact information, creation of bleeding disorder protocol (pre-treatment vs. post-treatment)

Spamalot – Monty Python



Panel Question

What if I am not sure if I should call the HTC for a question/concern? What is the best thing to do in this situation?



Emotional Well-Being

- Social workers discuss the emotional and social challenges of living with bleeding disorders
- The value of psychosocial support, addressing stress and navigating life challenges
- How to use social work services for support from mental health concerns to practical resources



Patient Education

- ▶ Importance of education on recognizing warning signs, managing symptoms at home and handling emergencies
- ▶ Nurses and social workers share how HTC's provide ongoing education and support to help you feel confident in your self-care
- ▶ Connecting to community resources and further education
- ▶ Networking for support

Panel Question

Can I connect with someone else that has the same diagnosis or is going through similar life events?



Panel Q&A

- Audience questions to the panel!



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!