American Society of Hematology

Pediatric-to-Adult Thalassemia Transition Program Action Plan

I. CREATE YOUR TEAM: Establish a pediatric thalassemia transition team

- People to consider include: Physicians, Advanced Practice Providers, Case Managers, Social Workers (SW), Psychologists, and Medical Assistants
- Gather support from leadership: Hematology Division Head, Chair of Pediatrics
  - Prepare an elevator speech on why establishing a Thalassemia Transition Program is essential
  - A Transition Program is a key part of a Comprehensive Thalassemia Center

II. CULTIVATE A TRANSITION PARTNERSHIP with an adult provider

- Find an adult provider
  - Consider reaching out to Cooley's Anemia Foundation to tap into their network of providers
- Establish a relationship with the adult provider and their thalassemia team
  - Make a communication plan (email, phone, or in-person)
  - Make a plan for the adult team to meet the patients

III. INTEGRATE INTO THE ELECTRONIC MEDICAL RECORD (EMR)

- Getsupport to set up the transition module in your EMR system. This can take a long time. To start, paper copies can be used and scanned into the EMR.

IV. START YOUR TRANSITION CLINIC

- Establish a method to identify transition-aged youth (ex. EMR can automatically identify by age)
- Create a tracking system to monitor % of patients who have undergone annual transition readiness survey, etc
  - Use the Transition Worksheet-Pediatric
- Starting at age 12 years old, have patients complete the Thalassemia Transition Readiness Assessment (TRA) annually
  - Can be done on paper, or via EMR module
  - Develop a clinic process for using the TRA
    - Determine who will administer the TRA
    - Determine who will review the answers
    - Determine who will identify which education to provide
    - Determine who goes over the education with the patient
- Have adult team meet the patients ≥ 18 years old annually at their pediatric visits either in person or virtually
- Provide financial assistance to ensure appropriate insurance is in place
- Transfer of Care: Sign out to adult thalassemia team
  - Use the Transition Worksheet-Adult
  - Sign Release of Information
  - Clinical Summary/Individualized Care Plan
    - Create this medical summary in the EMR
    - Communicate this information with adult provider
  - Other teams to include in communication:
    - Pediatric SW to sign out to Adult SW
    - Blood Bank
    - Subspecialty care–work with adult provider to see if there are specific thalassemia-focused subspecialists (cardiology, pulmonology, endocrinology, or GI) in the adult world
  - Confirm date of first adult appointment

V. FOLLOW UP POST-TRANSITION: Follow up 3, 6, and 12 months after transition to see how the patient is doing, any further assistance that can be provided by the pediatric team

VI. HOW DID WE DO?: Have your transitioned patients complete a post-transition survey and consider a quality improvement project to improve your program's transition process