Transitions

My Perspective

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About Me

- Adult hematologist
- Long standing interest in congenital blood disorders
- Currently care for ~12 individuals with transfusion dependent Thalassemia
  - Other transfusion dependent congenital blood disorders

Transition of care from Pediatrics to Adult Care for those with Congenital Disorders

- Hot Topic

- I personally feel we do less well in hematology compared to Cystic Fibrosis and Congenital Heart Disease

- Abrupt Change

Transitioning
A Tale of Two Care Cities

Pediatric Centered	Adult Centered
• **Nurturing**	• **Informing**
• **Parent Centered**	• **Patient Centered**
• **Universal funding**	• **Unfunded**
• **Family insurance provided**	• **Employment based insurance**
• **Paternalistic**	• **Total Autonomy**
• **Centralized**	• **Fragmented**
• **Informed providers**	• **Ignorant providers**

Adult Care of Transitioning Patients With Thalassemia

(Congenital Blood Disorders in General)

- Lack of Knowledgeable Providers
  - Goals of transfusions
  - Access to non invasive iron quantification
  - Lack of familiarity of chelation agents
  - Flexibility in transfusion appointments

- My overall impression is we do a bit better

- **Continued involvement and close communication with pediatrics**

- Excellent Nurse and Physician Assistant

- Access to Iron quantification

Issues I See

- Abrupt transition
  - Go from oldest person to youngest
  - May be around really sick patients
  - Infusion Centers and clinics may seem high volume impersonal

- Insurance
- Compliance with medications
  - "I'll deal with it later"

Advice

- Maintain Contact at least annually with a provider familiar with care of Thalassemia

- Ask Questions

- Stay up to date on insurance

- Think Long term/ Don't let this stop you.