

Collaborative Global Advocacy to Improve the Lives of Children and Families with Congenital Hyperinsulinism

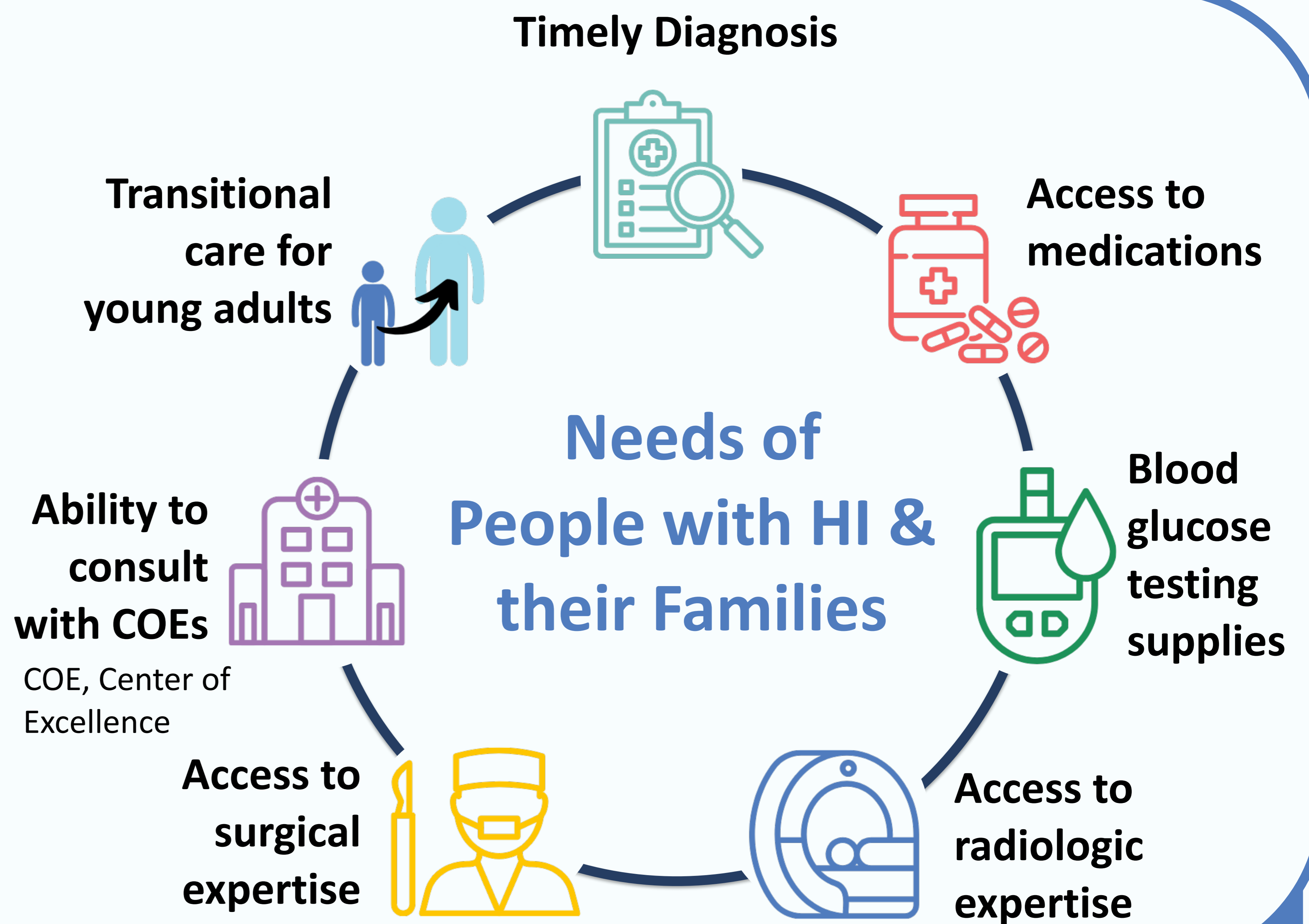
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Congenital Hyperinsulinism

Congenital Hyperinsulinism (HI) is a rare life-threatening condition leading to severe hypoglycemia. Hypoglycemia can lead to seizures, developmental delay, visual impairment, and death. Limited treatment options exist.



Congenital Hyperinsulinism International (CHI) is an international nonprofit organization focused on improving the lives of people with HI and their families

CHI established a **Collaborative Research Network (CRN)** in 2020



The CRN is made up of **62 members** from **17 countries** and includes:



Researchers



Rare disease advocates



Healthcare providers

All united around the common goal of improving the lives of people with HI through research and advocacy.



Met virtually and in-person to produce documents that could be used to assure optimal outcomes for people impacted by HI.

The **advocacy documents** will be used to convey:

- The medical and developmental needs of children with HI
- Urgency of timely diagnosis
- Access to medications and blood glucose testing supplies

This approach to advocacy could serve as a template for others working with rare diseases.



Advocacy Statement



List of Essential Medical Care, Medication, Supplies, and Services



Scan QR code to access HI Advocacy documents

Available in English, French, German, Portuguese, and Spanish

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HI community needs informed development of documents