

Utilizing Global Collaboration to Develop an Accessible Lay Summary of the International Guidelines for the Diagnosis and Management of Hyperinsulinism

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Congenital Hyperinsulinism (HI) is a life-threatening condition that results in severe hypoglycemia and can lead to neurological damage.

Hypoglycemia can lead to seizures, developmental delay, visual impairment, and death.

HI Care is complex and challenging, in 2024 the *International Guidelines for the Diagnosis and Management of Hypoglycemia* were published as a consensus document.

Congenital Hyperinsulinism International (CHI)

CHI is a global nonprofit organization focused on improving the lives of people with HI and their families.

CHI established a **Collaborative Research Network (CRN)** in 2020 and a **prioritized research agenda** in 2022.

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



Researchers



Rare disease advocates



Healthcare providers



CHI CRN Care Guidelines Group

- ✓ Translates complex clinical recommendations into more universally understandable language
- ✓ Easily accessible online in simplified language with complementary graphics to aid understanding
- ✓ Focused on readability including sentence length and structure, vocabulary, clarity, layout, and increased images
- ✓ Readability Grade Level / Ease Score: 10th – 12th Grade

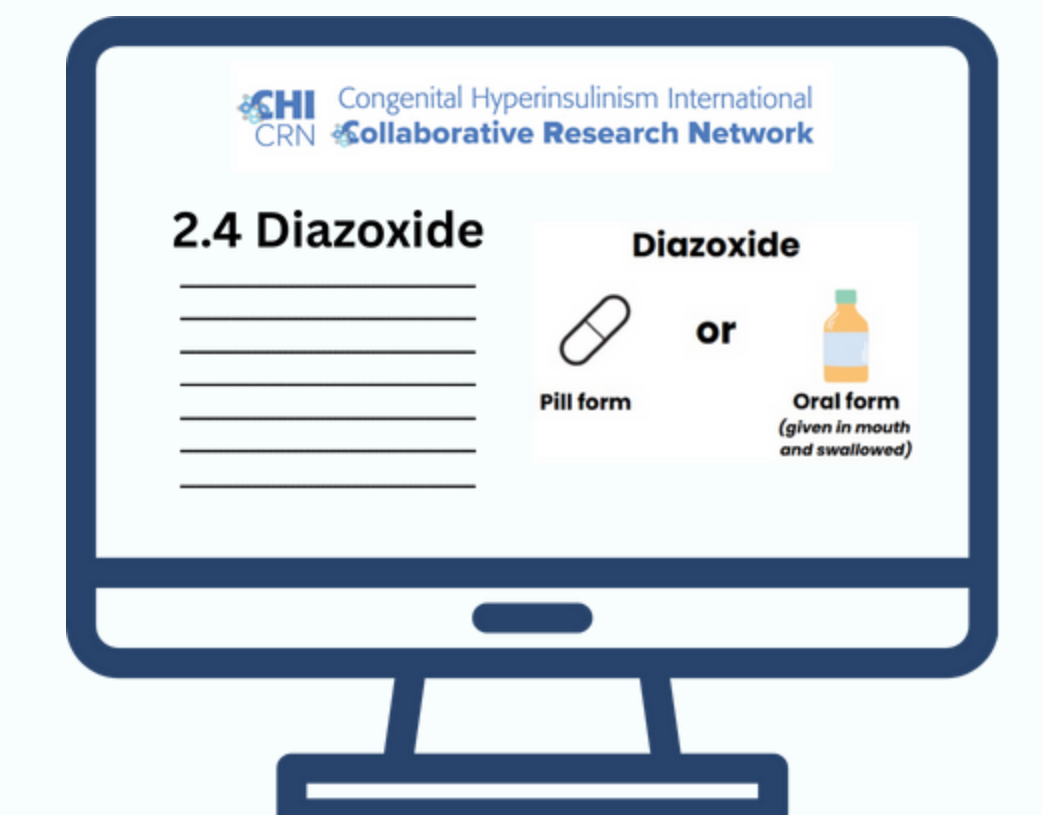
Created an accessible complementary version of the documents for patients/families and non-specialist audiences

Complex clinical guidelines



Goal: Enhance shared decision-making between families and physicians

Directly mapped to lay summary



Read the Simplified Care Guidelines!