LIMITATIONS OF CURRENT SCREENING GUIDELINES FOR NEONATAL HYPOGLYCEMIA

Lauren N. Lopez, Kristen E. Rohli, Tai L. S. Pasquini, Julie Raskin

Congenital Hyperinsulinism International, Glen Ridge, New Jersey, USA

INTRODUCTION

- Congenital hyperinsulinism (HI) is the leading cause of hypoglycemia in newborns.
- In HI, uncontrolled insulin production leads to severe hypoglycemia with a high risk of neurological damage.
- The first step in diagnosing HI is a blood glucose test, however there is currently no universal newborn screening for HI.
- Clinical guidelines focus on screening neonates with at least one risk factor for hypoglycemia: preterm, small or large for gestational age, or infant of diabetic mother.
- **The aim of this retrospective study was to review self-/caregiver-reported risk factors at birth in individuals who were ultimately diagnosed with HI and compare the neurodevelopmental outcomes between individuals screened for hypoglycemia and those who were not.**

METHODS

The HI Global Registry (HIGR) is the only international patient-powered registry for people with HI.

People with HI or their caregivers consented to participate in HIGR

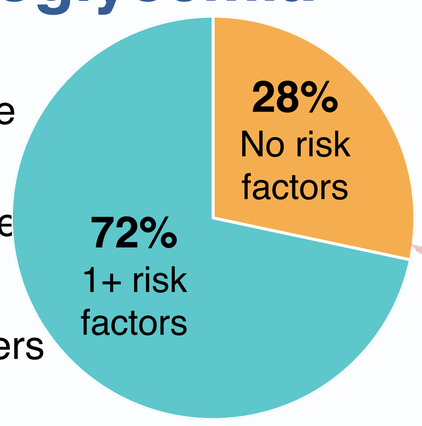
N = 180
Had a confirmed diagnosis of HI and completed the required surveys

Categorical data reported using descriptive statistics

RESULTS

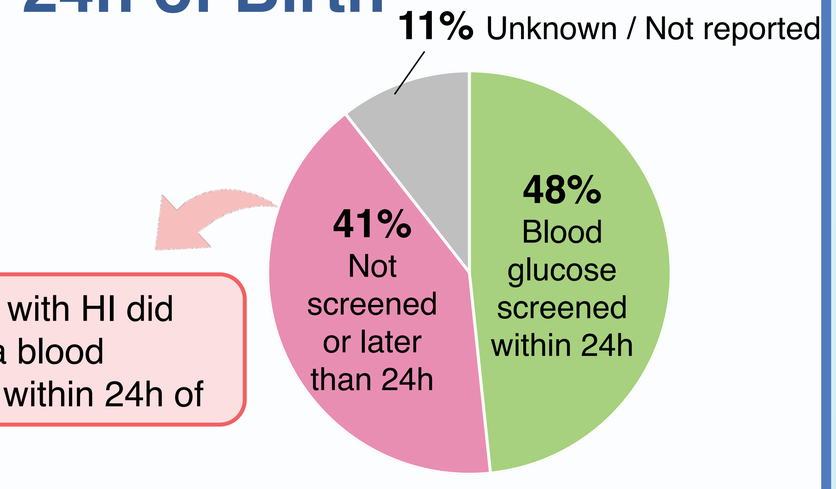
Risk Factors for Hypoglycemia

- Preterm (< 37 weeks)
- Small for gestational age (< 10th percentile)
- Large for gestational age (> 90th percentile)
- Infants of diabetic mothers



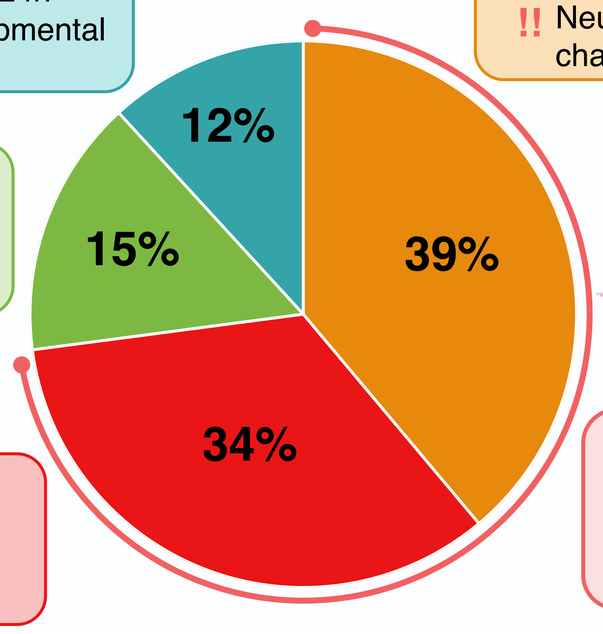
28% Of neonates with HI wouldn't qualify for hypoglycemia screening under most current guidelines

Blood Glucose Test within 24h of Birth



41% Of neonates with HI did not receive a blood glucose test within 24h of birth

Neurodevelopmental Outcomes



!! Blood glucose NOT screened within 24h
✓ No neurodevelopmental challenges*

✓ Blood glucose screened within 24h
!! Neurodevelopmental challenges

✓ Blood glucose screened within 24h
✓ No neurodevelopmental challenges*

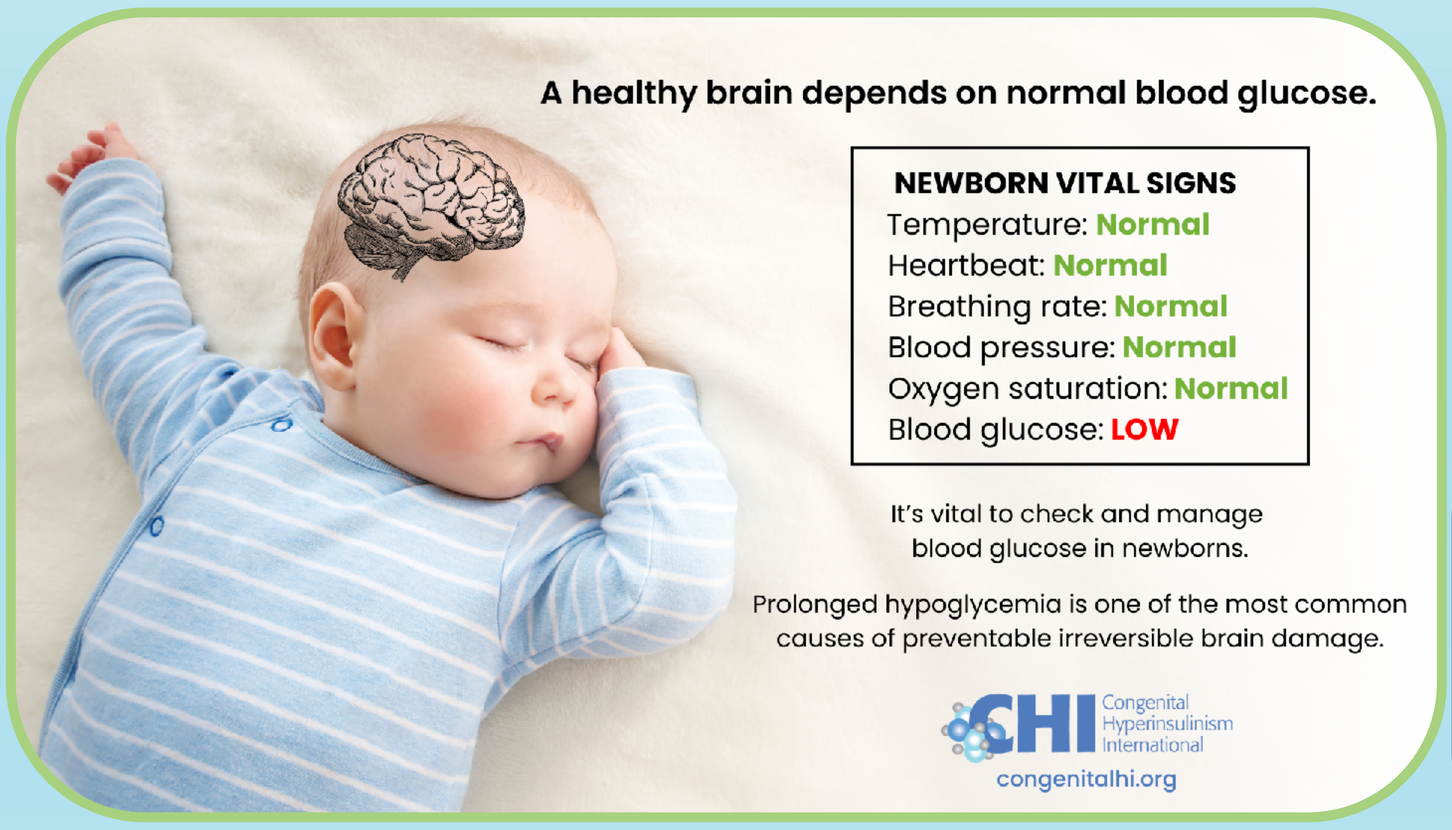
!! Blood glucose NOT screened within 24h
!! Neurodevelopmental challenges

73% Reported 1+ adverse neurodevelopmental outcome

** Participants age 3 years or younger excluded – too young to assess many neurodevelopmental challenges*

CONCLUSIONS

- This data highlights the limitations of current screening practices, which do not identify all neonates with HI.
- Furthermore, screening alone is not sufficient to prevent neurological damage, as shown by 39% of participants with neurological damage despite receiving a blood glucose test within 24h of birth. Fast, appropriate management to limit hypoglycemia is also critical.
- Adverse neurodevelopmental outcomes are common in HI, and could be caused by undiagnosed prolonged hypoglycemia.
- Neurodevelopmental outcomes could be improved with universal neonatal glucose screening and proper medical and/or surgical management of HI.



GLUCOSE IS A VITAL SIGN

"In hospital maternity wards and pediatricians' offices, glucose is a vital sign that must not be ignored."

Diva De Leon-Crutchlow, MD, director of Children's Hospital of Philadelphia's Hyperinsulinism Center and Chief of the Division of Endocrinology at CHOP.

Learn more about this campaign

The authors would like to thank the patients and caregivers for their contribution to HIGR and the HIGR Steering Committee for their guidance.
CHI receives funding for HIGR from Rezolute, Zealand Pharma, Hanmi, Rhythm, and many private sponsors.
CHI also receives funding for HIGR from the EU LightCure grant #101080327.

Learn more about HIGR!