Communication in the Neonatal Intensive Care Unit for Children Diagnosed with Hypoxic Ischemic Encephalopathy - Parent Survey

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Parent Survey

Alteration of consent: You are being asked to participate in an anonymous research project. Through the Newborn Brain Society collaboration, Hope for HIE's Betsy Pilon and Annie Goeller are co-writing a chapter to be featured in Seminars in Fetal & Neonatal Medicine titled "Supporting parents during hypothermia".

Drs. Alexa Craig and Monica Lemmon are co-writing the chapter with Betsy and Annie, bringing their clinical expertise and research interest in improving communication with families in the NICU. Please review the following and decide if you wish to participate.

WHAT ARE MY RIGHTS AS A PARTICIPANT? Taking part in this survey is your choice. You may choose not to take part at any time.

WHY IS THIS STUDY BEING DONE? The purpose of the study is to learn more about the parent experience of the NICU for children diagnosed with hypoxic ischemic encephalopathy (HIE) and/or treatment with therapeutic hypothermia.

WHAT IS INVOLVED IN THE STUDY? You are being asked to complete a survey that may be as long as 28 questions. We estimate that it will take you approximately 10-15 minutes to complete.

WHAT ARE THE RISKS OF THE STUDY? Potential risks include loss of anonymity if you includes personal information. To minimize this risk, we will not ask for or record any identifiable information.

WHY AM I BEING ASKED TO RELEASE THIS INFORMATION? Your responses are valued and will help us understand your experiences in the NICU. Using a survey to ask parents who participate in Hope for HIE allows us to get information from a large number of families.

WHO WILL SEE THIS INFORMATION? Study personnel, members of the Maine Medical Center Institutional Review Board, personnel from the Office of Human Research Protections or any regulatory agency may see the anonymous responses to the survey. The information collected is the property of the research team and you will not be able to get it back. In the event of any publication regarding this study, your identity and the identity of your institution, will not be disclosed. Efforts will be made to keep your information confidential including de-identification, password protection and secured storage. We cannot guarantee absolute confidentiality.

WHOM DO I CONTACT IF I HAVE QUESTIONS OR PROBLEMS? For questions about the study contact Betsy Pilon (betsy@hopeforhie.org), OR Annie Goeller (annie@hopeforhie.org) OR Dr. Alexa Craig at (207) 396-7337 OR Dr. Monica Lemmon at (919) 668-0477. For questions about your rights as a research participant, contact the Maine Medical Center Institutional Review Board, a group of people who review the research to protect your rights, at 207-661-4474.

If you choose not to participate, please select "No" and the survey will be complete.

○ Yes ○ No

What role do you play in the life of a child with HIE?	○ mother ○ father ○ grandparent ○ caregiver ○ other

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Please describe your "other" role in the life of a child with HIE.

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How old were you when your child was born?

○ less than 18 years
○ 19-25 years
○ 26-34 years
○ 35-44 years
○ more than 45 years

In what year was your child born?
*Please type in a 4-digit year, e.g. 1981 or 1996 or 2004 or 2011

____

How do you identify your race/ethnicity?
*Please select all that apply

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or Pacific Islander
☐ White or Caucasian
☐ Other:

Please tell us additional information about your race or ethnicity.

____

Do you know the cause of your child's HIE? ○ Yes ○ No

Please share what you understand to be the cause(s) of your child's HIE.
(Check all that apply)

☐ Placental abruption
☐ Other placental issue (insufficiency, blood flow issues, placental previa, etc.)
☐ Umbilical cord issues (compression, prolapse, true knot, entanglement, etc.)
☐ Shoulder dystocia
☐ Uterine rupture
☐ Traumatic delivery
☐ High blood pressure/Preeclampsia/HELLP Syndrome
☐ Gestational diabetes or severe hypoglycemia post-birth
☐ FetoMaternal Hemorrhage
☐ Meconium Aspiration
☐ HIE in childhood (near-SIDS, cardiac arrest, accidental near drowning, etc.)
☐ Other:

What is the "other" cause of your child's HIE?

____

Was you child treated with therapeutic hypothermia? ○ yes ○ no ○ I do not know

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Please indicate the level of the SARNAT scale or the severity of encephalopathy that was given to your child in the NICU.

○ Mild
○ Moderate
○ Severe
○ My child was not given a level
○ I don't know if my child was given a level

Did your child have an MRI of the brain while in the NICU?	○ yes ○ no ○ I do not know
Was there brain injury present on the MRI?	○ yes ○ no ○ I don't know

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If your child had brain injury on their MRI, please indicate the degree of injury present:

○ mild
○ moderate
○ moderate-severe
○ severe
○ the degree of injury was not communicated with me
○ I don't know the degree of injury

Please describe your child's clinical outcome thus far:

○ Within typical developmental ranges for the age
○ Mildly impacted
○ Moderately impacted
○ Severely impacted
○ Loss from HIE

Please indicate any subsequent diagnoses your child has been given:
(Check all that apply)

☐ None, my child is within typical developmental ranges for age
☐ Cerebral palsy
☐ Epilepsy
☐ Cortical Vision Impairment
☐ Delayed Visual Maturation
☐ Strabismus/amblyopia (eye alignment issues)
☐ Hearing Loss
☐ Reflux
☐ Feeding & Swallowing Issues
☐ Autism
☐ Learning Issues (Dyslexia, Dysgraphia, Visual Processing, Auditory Processing, etc.)
☐ Attention Issues (ADHD, ADD, inattentive ADHD, etc.)
☐ Dystonia
☐ Kidney Issues
☐ Apnea
☐ Secondary Microcephaly
☐ Other:

Please describe other diagnoses you child with HIE has received.

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What type of cerebral palsy has you child been diagnosed with?

○ Hypotonic
○ Dyskinetic
○ Ataxic
○ Spastic Diplegia
○ Spastic Triplegia
○ Spastic Quadraplegia
○ Spastic Hemiplegia
○ Dystonic

What level of cerebral palsy, according to the Gross Motor Function Classification System (GMFCS), does your child have?
*For more information about GMFCS, please click here to visit this website

○ GMFCS, Level 1
○ GMFCS, Level 2
○ GMFCS, Level 3
○ GMFCS, Level 4
○ GMFCS, Level 5
○ I don't know

Did you child experience seizures in the NICU? ○ Yes ○ No ○ I don't know

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If your child has persistent seizures or has been given a diagnosis of epilepsy, please indicate what types of seizures occur or have occurred?
(Check all that apply)

☐ Infantile Spasms
☐ Lennox-Gastaut Syndrome
☐ Tonic-Clonic Seizures
☐ Absence Seizures
☐ Electrical status epilepticus in sleep (ESES)
☐ Complex Partial Seizures
☐ Myoclonic Seizures
☐ Atonic Seizures
☐ unsure
☐ my child does not have seizures

Please rank the quality of communication you experienced while in the NICU with your child with HIE.

○ 1 Very dissatisfied
○ 2
○ 3
○ 4
○ 5 Greatly satisfied

What was most effective way information was communicated to you?

____

What would have improved communication for you while you were in the NICU?

____

At what point(s) did communication occur regarding the potential outcomes/prognosis of your child with HIE? (Check all that apply)

☐ Immediately following birth
☐ During hypothermia treatment
☐ After the MRI
☐ Prior to discharge
☐ I don't know/I did not hear about potential outcomes
☐ Other:

Please tell us about other communication that happened regarding outcomes/prognosis for your child.

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At what point(s) would you have liked to receive communication about the potential outcomes/prognosis of your child with HIE? (Check all that apply)

☐ Immediately following birth
☐ During hypothermia treatment
☐ After the MRI
☐ Prior to discharge
☐ I don't know
☐ Other

Please tell us about other preferences you have about when communication could be best achieved.

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Please rank the level of involvement in care you experienced while in the NICU with your child with HIE (i.e. helping with baths, changing diapers, feeding, etc.).

○ 1 Very dissatisfied
○ 2
○ 3
○ 4
○ 5 Greatly satisfied

What was most effective strategy to involve you in your child's care?

____

What could have improved your involvement in your child's care during the NICU?

____

What are the top five items that made the biggest impact on your care and communication in the NICU with your child, or would've have made the biggest impact?

☐ Daily rounds
☐ Coordinated communication with the team
☐ Involvement in care (feeding, bathing, diapering) of your child
☐ Patient education materials
☐ Goals for discharge
☐ Understanding monitoring equipment
☐ Understanding HIE
☐ Understanding the various diagnostic equipment (MRI, EEG, etc.) and the results
☐ Potential prognosis communication
☐ Resources to connect with other families, foundations, etc.
☐ Other:

Please explain more about what "other" things would have be helpful.

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Looking back, what type of information about the future was or would have been helpful to you in the NICU?

☐ Developmental outcomes
☐ Epilepsy
☐ Impact on family life
☐ Connection to peer support
☐ Financial impact
☐ Other

Please explain more about other types of information that would have been helpful.

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What else would you like NICU providers to know about improving your experience?

Thank you for your valuable contributions to this survey.