



## Outcomes of Children Born Extremely Preterm Miami Neonatology 2020—44th Annual International Conference

### Susan R. Hintz, MD, MS Epi

Robert L. Hess Family Professor of Neonatal and Developmental Medicine  
Professor of Pediatrics and, by courtesy, of Obstetrics & Gynecology  
Senior Associate Chief, Division of Neonatal and Developmental Medicine  
Stanford University School of Medicine  
Director, The Fetal and Pregnancy Health Program  
Lucile Packard Children's Hospital Stanford  
Palo Alto, California

### Key Takeaways

- Survival rates of extremely preterm infants have increased over the last 2 decades
- Neurodevelopmental impairment is a major morbidity for extremely preterm infants
- Rates of major neurosensory disability have not improved; these rates are also not increasing
- Significance of long-term functional and quality-of-life outcomes
- Outcomes important to families and better preparing families
- Academic performance is challenging for children born extremely preterm
- Variation or instability is prevalent across categories between the 18–22 month assessment and the 6–7 year assessment
- Sociodemographic factors and other disparities found to be associated with nonreferral and getting to the first follow-up visit
- Importance of earlier intervention in the NICU, including family-integrated care intervention

### Supplemental Questions

*Successful completion of this activity is achieved by individually reflecting on, or discussing as a group, the following questions and their implications.*

1. How do you measure neurodevelopmental outcomes in very preterm infants?

*See page 4 of the transcript.*

2. How do you determine cognitive assessment on extremely preterm infants?

*See page 5 of the transcript.*

3. How do you implement early interventions with motor functional challenges?

*See page 13 of the transcript.*

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4. How do you interpret long-term neurodevelopmental impairment (NDI) outcome issues from available study data?

*See page 5 of the transcript.*

5. How have long-term NDI studies helped you in your practice when speaking with parents and caregivers?

6. What are some challenges in your practice when preparing parents and caregivers for potential rehospitalization, as well as medical and special services utilization?

*See page 10–11 of the transcript.*

7. How do you determine the most important outcomes for the family with children who were born extremely preterm?

*See page 14 of the transcript.*

8. What interventions have you implemented to meet the needs of your preterm infant patients?

9. What can you do better in the NICU with early intervention to address NDI?

*See page 13 of the transcript.*

10. How do you think about earlier interventions as a continuum from the NICU, through transition-to-home, and longer follow-up?

*See page 13 of the transcript.*

11. What do you do in your clinical practice to improve the pathway for referrals and first visits?

*See page 12–13 of the transcript.*

### Suggested Reading and References

Adams-Chapman I, Heyne RJ, DeMauro SB, et al. Neurodevelopment impairment among extremely preterm infants in the Neonatal Research Network. *Pediatrics*. 2018;141(5):e20173091. doi:10.1542/peds.2017-3091

Carter FA, Msall ME. Long-term functioning and participation across the life course for preterm neonatal intensive care unit graduates. *Clin Perinatol*. 2018;45(3):501-527. doi:10.1016/j.clp.2018.05.009

Cheong JLY, Anderson PJ, Burnett AC, et al. Changing neurodevelopment at 8 years in children born extremely preterm since the 1990s. *Pediatrics*. 2017;139(6):e20164086. doi:10.1542/peds.2016-4086

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Cheong JLY, Lee KJ, Boland RA, et al. Changes in long-term prognosis with increasing postnatal survival and the occurrence of postnatal morbidities in extremely preterm infants offered intensive care: a prospective observational study. *Lancet Child Adolesc Health*. 2018;2(12):872-879. doi:10.1016/S2352-4642(18)30287-6

Haslam MD, Lisonkova S, Creighton D, et al. Severe neurodevelopmental impairment in neonates born preterm: Impact of varying definitions in a Canadian cohort. *J Pediatr*. 2018;197:75-81.e4. doi:10.1016/j.jpeds.2017.12.020

Hintz SR, Gould JB, Bennett MV, et al. Referral of very low birth weight infants to high-risk follow-up at neonatal intensive care unit discharge varies widely across California. *J Pediatr*. 2015;166(2):289-95. doi:10.1016/j.jpeds.2014.10.038

Hintz SR, Gould JB, Bennett MV, et al. Factors associated with successful first high-risk infant clinic visit for very low birth weight infants in California. *J Pediatr*. 2019;210:91-98.e1. doi:10.1016/j.jpeds.2019.03.007

Hintz SR, Vohr BR, Bann CM, et al. Preterm neuroimaging and school-age cognitive outcomes. *Pediatrics*. 2018;142(1):e20174058. doi:10.1542/peds.2017-4058

Horbar JD, Edwards EM, Ogbolu Y. Our responsibility to follow through for NICU infants and their families. *Pediatrics*. 2020;146(6):e20200360. doi:10.1542/peds.2020-0360

Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: A family perspective. *Semin Perinatol*. 2016;40(8):571-577. doi:10.1053/j.semperi.2016.09.009

Kilbride HW, Aylward GP, Carter B. What are we measuring as outcome? Looking beyond neurodevelopmental impairment. *Clin Perinatol*. 2018;45(3):467-484. doi:10.1016/j.clp.2018.05.008

Marlow N, Wolke D, Bracewell MA, Samara M; EPICure Study Group. Neurologic and developmental disability at six years of age after extremely preterm birth. *N Engl J Med*. 2005;352(1):9-19. doi:10.1056/NEJMoa041367

Pai VV, Kan P, Bennett M, Carmichael SL, Lee HC, Hintz SR. Improved referral of very low birthweight infants to high-risk infant follow-up in California. *J Pediatr*. 2020;216:101-108.e1. doi:10.1016/j.jpeds.2019.08.050

Petty J, Whiting L, Green J, Fowler C. Parents' views on preparation to care for extremely premature infants at home. *Nurs Child Young People*. 2018. doi:10.7748/ncyp.2018.e1084

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Serenius F, Ewald U, Farooqi A, et al. Neurodevelopmental outcomes among extremely preterm infants 6.5 years after active perinatal care in Sweden. *JAMA Pediatr.* 2016;170(10):954-963. doi:10.1001/jamapediatrics.2016.1210

Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev.* 2015;(11):CD005495. doi:10.1002/14651858.CD005495.pub4

Synnes A, Luu TM, Moddemann D, et al. Determinants of developmental outcomes in a very preterm Canadian cohort. *Arch Dis Child Fetal Neonatal Ed.* 2017;102(3):F235-F234. doi:10.1136/archdischild-2016-311228

Treyvaud K. Parent and family outcomes following very preterm or very low birth weight birth: a review. *Semin Fetal Neonatal Med.* 2014;19(2):131-5. doi:10.1016/j.siny.2013.10.008

Treyvaud K, Ure A, Doyle LW, et al. Psychiatric outcomes at age seven for very preterm children: rates and predictors. *J Child Psychol Psychiatry.* 2013;54(7):772-9. doi:10.1111/jcpp.12040

van Wassenaer-Leemhuis AG, Jeukens-Visser M, van Hus JW, et al. Rethinking preventive post-discharge intervention programmes for very preterm infants and their parents. *Dev Med Child Neurol.* 2016;58 Suppl 4:67-73. doi:10.1111/dmcn.13049

Vohr B, McGowan E, Keszler L, O'Donnell M, Hawes K, Tucker R. Effects of a transition home program on preterm infant emergency room visits within 90 days of discharge. *J Perinatol.* 2018;38(2):185-190. doi:10.1038/jp.2017.136

Vohr BR, Yatchmink YE, Burke RT, et al. Factors associated with rehospitalizations of very low birthweight infants: impact of a transition home support and education program. *Early Hum Dev.* 2012;88(7):455-60. doi:10.1016/j.earlhumdev.2011.10.011

Wolke D, Baumann N, Busch B, Bartmann P. Very preterm birth and parents' quality of life 27 years later. *Pediatrics.* 2017;140(3):e20171263. doi:10.1542/peds.2017-1263

Woodward LJ, Hüppi PS. Chapter 11: Neurodevelopmental follow-up. In: *Volpe's Neurology of the Newborn.* 6th ed. Elsevier; 2018:255-272.