

The facts about kernicterus

- Kernicterus is an easily preventable developmental disability
- Kernicterus is caused by severe newborn jaundice
- Jaundice is caused by elevated bilirubin levels in the bloodstream. Bilirubin is the waste product that results from the breakdown of hemoglobin molecules from worn out red blood cells.
- Jaundice occurs in more than 60% of all newborns
- Changes in healthcare practices, including the early discharge of newborns from the hospital, have made it more difficult to detect jaundice
- Severe jaundice can result in permanent brain damage
- Children with kernicterus may die or develop cerebral palsy, hearing loss, dental enamel hypoplasia, or mental retardation
- Kernicterus was effectively eradicated in the 1970s, but reemerged in the 1990's
- Currently, there is no treatment that can lessen the severity of brain damage caused by Kernicterus



Hospitals urged to test for rare disorder (severe jaundice) among newborns. *USA Today*, May 2, 2001

Strategies for preventing kernicterus

- Conduct predischarge bilirubin measurement with use of a percentile-based nomogram to predict the risk of hyperbilirubinemia in newborns and to guide follow up
- Adopt policies and procedures that allow nurses to take bilirubin measurements in the absence of a doctor's order
- Follow AAP Practice guidelines for management of hyperbilirubinemia in the healthy term newborn

For additional recommendations, visit the PICK Web site at www.pickonline.org



The PICK promise

PICK is committed to pursuing interventions – both currently available and emerging – that provide children with kernicterus the opportunity and means to realize their maximum potential and enjoy the highest quality of life

possible. PICK actively partners with organizations and individuals engaged in research to promote new therapies and treatments for disabilities like kernicterus. These new areas of interest include stem-cell research and deep brain stimulation.

PICK Partners:



For additional information about PICK, please visit our Web site at www.pickonline.org or call (312) 274-9695
One Superior Place,
Suite 2410
Chicago, IL 60610

CDC and HHS support the education and prevention efforts of P.I.C.K.

Partnership



Prevention



& Promise



Parents Working for Change

Parents of Infants and Children with Kernicterus (PICK)

was founded in late 2000 by a group of parents whose children suffer from kernicterus. A not-for-profit organization, PICK promotes awareness,

prevention, and treatment of kernicterus. The organization's success is due to a unique operational model that emphasizes active partnerships with healthcare institutions and agencies as a means of achieving change.



“One case of kernicterus in the United States is one case too many.”

Marshalyn Yeargin-Allsopp, M.D., Medical Epidemiologist,
National Center on Birth Defects and Developmental
Disabilities, Centers for Disease Control and Prevention



“I was so frustrated, they were telling me to take him home and put him in the sunlight and that would take care of the jaundice. It didn't. Now, we're living with the consequences.”

Kathleen Haus, RN, PICK mother

Organizational goals

- Develop an effective parent/healthcare partnership model that is family-centered and systems-based for addressing preventable disabilities in newborns.
- Prevent kernicterus through a universal, systemwide program that includes education, objective bilirubin screening, follow-up care, diagnosis, and treatment.
- Provide comfort and support to families with children who suffer from kernicterus.
- Identify and support effective treatments and therapies that will improve the quality of life for children with kernicterus.
- Implement a structure of accountability for reported cases of hyperbilirubinemia.

“The PICK parents have melded together a demand for health system change with a sincere offer to partner for change. It's a powerful model for making healthcare both safer and more patient centered.” Martin J. Hattie, President, Partnership for Patient Safety

Progress and Partnerships

- Invited by the Agency for Healthcare Research and Quality (AHRQ) to give testimony on kernicterus during the first national summit on patient safety and medical error.
- Organized “Strategies for a Systemwide Change in the Management of Neonatal Hyperbilirubinemia to Prevent Kernicterus,” the first systemwide consumer and healthcare-industry workshop for kernicterus.
- Worked with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) on the April 2001 Sentinel Event Alert on kernicterus prevention.
- Worked with the Centers for Disease Control and Prevention (CDC) on the June 2001 *Morbidity/Mortality Weekly Report* (MMWR) which was dedicated to the subject of kernicterus.
- Recognized at the 2001 Patient Safety Partnership Symposium (Stories for Success), for bringing about change through effective partnerships with the healthcare system.
- Advocated successfully to have kernicterus classified as a “Never Event” by the National Quality Forum (NQF).
- Partnered with the Pennsylvania Hospital on a CDC grant aimed at research and prevention of kernicterus.