Helping New Jersey’s Sudden Infant Death Syndrome Center Reduce Infant Deaths

What was the problem/situation?

An average of 70 New Jersey families whose infants have died suddenly and unexpectedly are referred each year to the Sudden Infant Death Syndrome Center of New Jersey (SCNJ), a program of Rutgers Robert Wood Johnson Medical School and Hackensack University Medical Center. As Program Director of the SCNJ, Dr. Barbara M. Ostfeld is always looking for additional tools, data, partnerships, and funding to help enhance services for New Jersey families whose infants have died, and to help prevent additional infant deaths by promoting safe infant sleep practices. The SCNJ tackles many issues related to sudden and unexpected infant deaths: providing bereavement support for families; conducting research into the etiology of sudden and unexpected infant death; providing education and advocacy for the training of health, child care and social service providers and new parents consistent with the American Academy of Pediatrics’ evidence-based safe infant sleep guidelines; developing risk factor profiles associated with an elevated risk of Sudden Infant Death Syndrome (SIDS) and other sleep related infant deaths by maternal and child demographics, region, and other factors; evaluating where unmet needs exist; and obtaining additional funding to better serve the needs of New Jersey families.

How was Tracking involved?

The New Jersey Environmental Public Health Tracking project (generally known as EPHT or Tracking) has partnered with the New Jersey Department of Health.
(NJDOH) Center for Health Statistics to make New Jersey’s health and environmental data publically available through the NJ State Assessment Health Data (NJSHAD) system. NJ Tracking is working with NJDOH partners to make NJSHAD the premier “one stop shopping” location for health data and statistics for a variety of New Jersey’s communities: the general public; advocacy groups; local environmental and health officials; public health and medical professionals; and officials at local, county and state agencies. By design, NJSHAD serves the whole of NJDOH, and is structured to provide both queryable datasets and brief fact sheets which explain and frame what the data show. Queryable datasets available on NJSHAD (births; deaths; infant and fetal mortality; inpatient hospitalizations; and Behavioral Risk Factor Survey data) allow interested researchers and citizens to ask their own questions and to filter datasets by demographics, geographical region, cause of hospitalization or death, and other variables.

What action was taken to resolve the problem?

Dr. Ostfeld regularly uses NJSHAD in four distinct ways to enhance the SCNJ’s etiological research and educational outreach:

- to conduct etiological research on sudden and unexpected infant mortality by population group, maternal and infant characteristics, and other risk factors using the infant and fetal mortality data query;
- to identify which New Jersey communities have high risk populations using the birth query so that enhanced educational outreach can be conducted within high risk families, institutions, and providers in these communities;
- to monitor and publish the finalized rates of SIDS and safe-sleeping practices in New Jersey and the United States by year, and demographic groups using, in part, the NJSHAD SIDS and Safe Infant Sleep indicators;
- to educate parents, infant caregivers, and medical professionals regarding safe sleep practices which help prevent sudden and unexpected infant deaths through the information, resources and outreach programs provided by Dr. Ostfeld and described in the NJSHAD SIDS and Safe Infant Sleep indicators.

As stated by Dr. Ostfeld, “NJSHAD gives us a very clear picture of infant mortality drilled down to the regional and demographic level. NJSHAD assists me in identifying many of
the risk factors associated with diagnoses related to sudden unexpected infant death (SUID) in New Jersey for further study. Because NJSHAD has so many options to individualize queries by infant and maternal characteristics, I can develop profiles of risk for population groups and regions. We use these risk profiles as we implement our educational outreach campaigns, which are based on the national campaign called Safe to Sleep®. While NJSHAD doesn’t contain information on all behavioral risks related to SUID, it does have a wealth of essential information on prenatal care, delivery, premature birth, gestational age, birth weight, APGAR scores, smoking, and maternal demographics including poverty. I can show our state’s health care providers very specific data on increased risk levels by maternal and infant characteristics, so that educational interventions can be enhanced for the most at-risk families. NJSHAD is definitely helping the SCNJ’s efforts to reduce the risk of infant deaths in New Jersey.”