STATE OF NEW YORK
EXECUTIVE CHAMBER
GEORGE E. PATAKI, GOVERNOR

Press Office
518-474-8418
212-681-4640
http://www.state.ny.us
FOR RELEASE:
IMMEDIATE, Wednesday
October 27, 2004

GOVERNOR ANNOUNCES HISTORIC EXPANSION OF NEWBORN SCREENING

New York's Program Will Be Most Comprehensive Free Screening Program in the Nation: Number of Diseases/Disorders Newborns Will Be Screened for Will Grow from 11 to 44

Governor George E. Pataki today announced an historic expansion of New York's Newborn Screening program - which will make New York State's infant disease and disorder detection effort the most comprehensive free newborn screening initiative in the nation.

From our current newborn screening program to our unique HIV maternal transmission testing initiative, to our historic commitment to expanding access to health care for millions through Child Health Plus no state in the nation has done more to protect its children from illness and disease than New York, Governor Pataki said. We must continue do everything we can to help New York's children get as healthy a start in life as possible.

We're proud that this new initiative will ensure that as new diseases emerge and the technology to detect and treat them advances, every child born with a treatable disease will receive an early diagnosis and the lifesaving treatment they need to grow up happy, healthy and strong, the Governor added.

New York's Newborn Screening program, operated by the State Health Department's Wadsworth Laboratory, currently detects 11 diseases and disorders. Blood is drawn from every newborn upon delivery and sent to Wadsworth for testing. Those samples testing positive undergo confirmatory testing, which triggers any necessary follow up medical care. Early detection and treatment of many of these diseases can diminish or eliminate any serious health consequences for the child, and even prevent death.

Under the Governor's new expansion initiative, the number of diseases and disorders screened will grow to 31 by the end of 2004. An additional expansion to be implemented by the Spring of 2005 will bring that total to 44, making it the most comprehensive free screening program in the nation.

Also today, the Governor directed the Health Department's Newborn Screening Task Force to regularly review emerging treatable diseases and advancing detection technology, in an effort to determine as soon as possible when additional screening tests can be added to New York's program. The Task Force is composed of physicians and researchers from numerous hospitals and research centers, as well as Health Department scientists.

Earlier this year, Governor Pataki lauded another historic achievement in the State's continuing fight against newborn disease, when he announced a dramatic 78 percent decline between 1997 and 2002 in the number of newborns in New York State who are infected with HIV.

That success is founded on 1996 legislation, known as the Baby AIDS law, championed and signed into law by Governor Pataki. Under that landmark legislation, the Governor directed the State Health Department to add HIV to the state's Newborn Screening program. Mothers whose babies' test positive for HIV are informed so that they can seek proper treatment, which is vital in preventing mother-to-child HIV transmission.

State Health Commissioner Antonia C. Novello, M.D., M.P.H., Dr.P.H, said, Our children deserve no less than our very best effort when it comes to protecting their health and preventing illness and disease. Since the day he took office, Governor Pataki has repeatedly made clear his continuing and unwavering commitment to protecting the health of our children and of all New Yorkers. Today is another example of that deep commitment.

Currently the State's newborn screening program tests for 11 conditions:

- Phenylketonuria (PKU)
- Maple Syrup Urine Disease (MSUD)
- Homocystinuria
- Galactosemia
- Biotinidase deficiency
- Medium chain acyl Co-A dehydrogenase deficiency (MCADD)
- Congenital hypothyroidism (CH)
- Congenital adrenal hyperplasia (CAH)
- Cystic fibrosis (CF)
- Sickle cell disease (SSD)
- HIV-1 exposure

Under the expansion announced today by the Governor, the following conditions, which fall under the general heading of metabolic disorders, will be added:

Conditions to be added to NYS newborn screening panel in 2004:

- 3-Hydroxy-3-methylglutaryl-CoA lyase deficiency (HMG)
- 3-Methylcrotonyl-CoA carboxylase deficiency (3-MCC)

- more -

- Argininosuccinic acidemia (ASA)
- Carnitine palmitoyl transferase II deficiency (CPT-II)
- Carnitine uptake defect (CUD)
- Carnitine-acylcarnitine translocase deficiency (CAT)
- Citrullinemia (CIT)
- Cobalamin A,B cofactor deficiency (Cbl A,B)
- Glutaric acidemia type I (GA-I)
- Isovaleric acidemia (IVA)
- Long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD)
- Methylmalonyl CoA mutase deficiency (MUT)
- Mitochondrial acetoacetyl-CoA thiolase deficiency (BKT)
- Mitochondrial trifunctional protein deficiency (TFP)
- Multiple acyl-CoA dehydrogenase deficiency (MADD, also known as GA-II)
- Multiple carboxylase deficiency (MCD)
- Propionic acidemia (PA)
- Short-chain acyl-CoA dehydrogenase deficiency (SCADD)
- Tyrosinemia (TYR)
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD)

Additional expansion to be completed by Spring 2005:

- 2-Methyl 3-hydroxy butyric aciduria (2M3HBA)
- 2-Methylbutyryl-CoA dehydrogenase deficiency (2MBG)
- 3-Methylglutaconic aciduria (3MGA)
- Argininemia (ARG)
- Carnitine palmitoyl transferase deficiency II (CPT-II)
- Carnitine palmitoyltransferase Ia deficiency (CPT-1A)
- Dienoyl-CoA reductase deficiency (DE REDUCT)
- Hypermethioninemia (MET)
- Isobutyryl-CoA dehydrogenase deficiency (IBG)
- Malonic aciduria (MAL)
- Medium chain ketoacyl-CoA thiolase deficiency (MCKAT)
- Medium/short-chain hydroxy Acyl-CoA dehydrogenase deficiency (M/SCHAD)
- Methylmalonic academia (Cbl C,D)