

NEWS RELEASE

Contact: Leslie Johnson 718-281-8546, ljohnson@stmaryskids.org
Burns Patterson, 917-575-9155, burns@hudson-pr.net
Patrice Radowitz, 516-870-1621, pradowitz@familyres.org

HEALTHCARE SUMMIT HIGHLIGHTS EXPANDING POPULATION OF CHILDREN AND YOUNG ADULTS WITH COMPLEX MEDICAL CONDITIONS 'AGING OUT' OF RESIDENTIAL TREATMENT OPTIONS

24,000 in Need of Services and Eventual Placement

Summit Led by St. Mary's Healthcare System for Children and Family Residences and Essential Enterprises Presents New Findings

(New York, NY) December 2, 2015 - Many people recognize that advances in medical care and technology have helped to expand the nation's geriatric population by providing improved treatment options and outcomes. Fewer realize, however, that these same factors are leading to an **expanding population of children with medical complexity**, as treatment allows children to survive and thrive in ways that were not possible just decades ago. These survival rates are positive news for children and their families, but the link to geriatric patients goes even further. It turns out that as these children become young adults, **families are often forced to consider geriatric nursing homes as residential treatment options for their children** due to a lack of appropriate care settings that can address the higher acuity and intense utilization needs of this emerging population.

Recently, St. Mary's Healthcare System for Children and Family Residences and Essential Enterprises, Inc. (FREE) hosted a healthcare summit at John Jay College in Manhattan – *New Horizons for Children and Young Adults with Medical Complexity in New York State* – that served as a forum for advancing solutions for children and young adults with medically complex conditions and, **for the first time, sought to accurately quantify the size of the most fragile children within this statewide population.** Panel sessions examined innovative new assessments, interventions, and models of care developed over the course of 2014 and 2015 to address the needs of this population.

The Children's Hospital Association estimates that 4% of all children in the United States, and 6% of all children on Medicaid, face issues of medical complexity. Approximately 10% of children with medical complexity comprise a narrower subset of children referred to as medically fragile (MF), who are most likely to be dependent on medical technology and in need of skilled nursing services. **Data released at the summit commissioned by St. Mary's Healthcare System for Children (prepared by Manatt Health Solutions and Dobson DaVanzo based on analysis of NYS Medicaid statistics) revealed there are nearly 24,000 children and young adults with MF in New York State. Moreover, 9100 of these young people are aging out of pediatric programs and services, without a clear plan for the future.**

More...

Age Specific Breakdown of Children with Medical Fragility in New York State*

**Source: St. Mary's Healthcare System for Children/Manatt Health*

- ❖ **13,200 Children with MF Age 0-20 in NYS Medicaid. Of these:**
 - ❖ 7,700 are Age 0-11 (younger children)
 - ❖ 2,500 are Age 12-15 (children in need of transition planning)
 - ❖ 1,200 are Age 16-17 (children near aging out)
 - ❖ 1,800 are age 18-20 (children aging out)

- ❖ **10,700 Young Adults with MF Age 21-36 in NYS Medicaid. Of these:**
 - ❖ 3,600 are Age 21-25 (recently aged out young adults)
 - ❖ 7,000 are Age 26-35 (aged out young adults)

- ❖ **Total of 9,100 are in the “Aging Out” Medically Fragile population range (Age 12-25)**

The population needs assessment revealed that young adults with medical fragility face significant discontinuities and gaps in service. Currently, children with MF are typically cared for by their families at home with extensive pediatric supports; a smaller number utilize specialty pediatric facilities, such as St. Mary's Hospital for Children in Bayside, NY, that are equipped to care for their complex needs. However, key services and supports used for children with MF are not available after age 18 or 21, leaving the young adult population and their families with a lack of options.

Edwin Simpser, MD, president and chief executive officer of St. Mary's Healthcare System for Children, commented, “As these children live longer and become adults, we have to ask ourselves, ‘what comes next?’ We must not only save lives, we must do everything we can to make those lives worth living. For the first time in our history, we have the data to prove what our anecdotal experiences have always shown – that while this population is rapidly growing, their needs are largely unmet as they age out of pediatric programs.” Simpser continued, “With our partners at FREE, we posed a simple question, ‘If this level of care can exist for St. Mary's Kids, why can't we work together to provide integrated care in the transitional years between childhood and adulthood?’ The answer is that we can and we must create care solutions for every young adult with medical complexity in New York.”

Despite a national and state-wide push to shift care from institutional to community settings, geriatric nursing homes are often the only option available with skilled nursing services – and even these may lack the technological and medical expertise required for this young population. The unique combination of medical, social, psychological and developmental needs simply cannot be met in a geriatric setting.

St. Mary's has taken a lead role nationally and within New York State to advocate for solutions and treatment options for children and young adults with medical complexity. With grant support from the New York State Office for People with Developmental Disabilities, St. Mary's has partnered with Family Residences and Essential Enterprises, Inc. (FREE) to develop a group home model of care and pilot program. St. Mary's and FREE are committed to partnering on community-based group homes with intimate patient size, often 8 or less, supervised 24/7 with skilled nurses and medical professionals.

More...

A second grant awarded to St. Mary's from the New York State Department of Health seeks to improve care for children and young adults who receive services at home through the implementation of an innovative Telehealth remote patient monitoring program. Both initiatives were presented at the Summit as examples of replicable programs to address the growing demand for appropriate services and supports.

Speakers at the November 2015 "New Horizons" summit included: Roger Bearden, Deputy Commissioner & General Counsel, NYS Office for People with Developmental Disabilities; Edwin Simpser, MD, President and CEO, St. Mary's Healthcare System for Children; Christopher Long, Ed.D, President Family Residences and Essential Enterprises; and parents of children with medical complexity who are currently dealing with the issues surrounding "aging out." Presentation links and the program agenda are available at <http://stmaryskids.org/summit>.

About St. Mary's Healthcare System for Children

St. Mary's Healthcare System for Children is a national leader in post-acute care for children with special healthcare needs and New York's largest provider of long-term care services to children with medically complex conditions and their families. St. Mary's provides intensive rehabilitation, specialized care, and education to children throughout the New York metropolitan area at its inpatient facility – St. Mary's Hospital for Children – at home, and in the community. A pediatric healthcare innovator, St. Mary's opened the first medical facility for children in New York City in the 1870s, and today remains the City's only pediatric post-acute care hospital. St. Mary's created the nation's first pediatric palliative care program, NY State's first long-term home healthcare program for children, the state's first certified home health agency for children and young adults with medical complexity, NYC's first certified pediatric traumatic brain injury program, and offers one of a select few interdisciplinary pediatric feeding disorder programs in the nation. Learn more at www.stmaryskids.org.

About Family Residences and Essential Enterprises, Inc. (FREE)

Family Residences and Essential Enterprises, Inc. (FREE) founded in 1977 and headquartered in Old Bethpage, benefits and proudly supports more than 4,000 individuals with intellectual disabilities, mental illness and traumatic brain injury. It is the mission of FREE to help individuals of all abilities realize their full potential. FREE provides a diverse array of supports and services including: housing, recovery services, transition to work, employment, day, community and family services, respite, crisis services, education and after-school support, primary and specialty health care and advocacy. For more information, please call 516-870-7000 or visit www.familyres.org.

###

The conference was developed under grant CFDA 93.778 from the U.S. Department of Health and Human Services, Center for Medicare & Medicaid Services. However, the opinions, results, findings and/or interpretations of data addressed do not necessarily represent the opinions, interpretations or policy of the U.S. Department of Health and Human Services, New York State Department of Health, Office for People with Developmental Disabilities, or the Federal Government. Population assessment and group home model work is funded by the NYS OPWDD-administered BIP Transformation fund. Remote patient monitoring work is funded by the NYS DOH-administered BIP Innovation Fund.