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**For Immediate Release**

## **Families Rally to Save Medicaid Program for Children who are Medically Fragile**

**Bartlett, IL**--About 140 people gathered in Bartlett on Tuesday to fight budget cuts to a Medicaid program that serves children with tracheostomies, ventilators, or central lines. This program, the Medically Fragile and Technology Dependent (MFTD) Waiver, is slated to receive a \$15 million budget cut according to Governor Pat Quinn's Medicaid plan.

The rally was inspired by Michelle Kish, a fifteen-year-old with Hallerman-Streiff Syndrome, a craniofacial syndrome that causes Michelle to be legally blind, hearing impaired, of short stature, and require a tracheostomy and ventilator to breathe. Michelle is also a pianist, dancer, and good student who is thinking of becoming a doctor or teacher.

Family members, friends, and neighbors marched through Michelle's neighborhood holding signs and banners in support of the MFTD Waiver. The rally focused on the importance of keeping kids like Michelle at home, which is three times cheaper than institutionalizing them in hospitals. Supporters called for funding of home care and continuation of programs like the MFTD Waiver to keep children where they belong, at home.

Michelle has received home nursing care through the MFTD Waiver for almost her entire life. This program has literally kept her alive, living and thriving in the community with her family and friends. Children like Michelle require around-the-clock monitoring and care, including ventilator monitoring, tracheostomy care, suctioning, tube feedings, and respiratory treatments. Since private insurance typically does not pay for home nursing care, the MFTD Waiver is a safety net for working and middle class families with catastrophic medical needs and expenses.

Governor Pat Quinn's budget proposal would cut \$15 million from the 500 children served by the program. Families above an income threshold could lose home nursing, less medically involved children could be eliminated from the program, and families could be asked to pay exorbitant monthly premiums to receive home nursing care. The state hopes to raise \$5.1 million from families in the program, or more than \$10,000 per family.

If Michelle lost her home nursing, she could no longer live at home, attend school, or continue to be a productive member of society. She would be forced into a hospital bed for the rest of her life. Ironically, once in the hospital, Medicaid is required by federal law to pay for her care, even though it costs three times more.

## **About MFTD Waiver Families**

MFTD Waiver Families is a group of about 50 concerned families of children on the Waiver or in other Illinois programs. We advocate for renewal of the MFTD Waiver to allow our children to continue living at home. Additional details about the Waiver and family stories may be accessed at <http://www.SaveMFTDWaiver.com>.

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For more information, please email [MFTDWaiver@gmail.com](mailto:MFTDWaiver@gmail.com). We have families available for interviews throughout most regions of the state. For sources of information cited, please see <http://SaveMFTDWaiver.com/sources.html>.