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TESTIMONY OF JEANNE MILSTEIN
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Good morning Senator Crisco, Representative Fontana, and members of the Committee on Insurance and Real Estate. My name is Jeanne Milstein and I am the Child Advocate for the State of Connecticut. I appreciate the opportunity to testify in support of **Raised Bill No. 5013, An Act Establishing a Catastrophic Medical Expenses Pool**. Today I am painfully cognizant of the difficult financial circumstances our state is in. But I feel the bill before you is an excellent example of ways we can be thinking about assisting Connecticut citizens as we re-build our systems of support in the future.

As you know, my role is to provide oversight of state-funded services to children. We have conducted a number of reviews and investigations and found many deficiencies in our systems of supports for families and their children – access to comprehensive health insurance chief among them. But what my staff and I are finding more and more is that there is an urgent need for families to have access to resources beyond health insurance.

Many Connecticut families face financial devastation associated with caring for a child with special health care needs. For many families whose children have chronic conditions, the expenses for medically necessary care outpace their private or public insurance plans' coverage limits every year, leaving the families with extraordinary out-of-pocket expenses. Many families see no choice but to turn to the state and institutionalize their children. The pool established by Bill No. 5013 would require a family to appeal the insurer's denial of coverage and submit proof of insurance to the Healthcare Advocate in order to request pool funds as a necessary and critical last resort.

Over the last few years my office has worked to support a similar pool of funds that would have provided relief to families of children with overwhelming medically related debt. Beyond health insured goods and services, expenses accrue from specialized transportation, home modifications, electric bills, special diets, and many other items that are necessary in the management of a catastrophic medical condition, but are not necessarily considered medically necessary. There will always be extraneous costs that will make or break a family: ramps for wheelchair accessibility; van conversions; enormous electrical bills to support life-sustaining equipment; and even parking fees that so many families accrue while providing bedside comfort to a frightened child experiencing a long-term hospitalization.

In times of such economic and emotional duress, families will be stressed as never before to care for their children and maintain mortgages, get to work, and manage daily costs of living. As we move forward in the broader discussion on universal health insurance, I hope we will keep

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move forward in the broader discussion on universal health insurance, I hope we will keep creative supports like a catastrophic cost pool in mind. We need these kinds of creative solutions to fill the gaps in our health care system and keep families together and functioning.