



10280 Chester Road, Cincinnati, OH 45215
P: (513) 772-4888 | thecurestartsnow.org

May 15, 2026

housejudiciary@rilegislature.gov

Dear Committee Members,

As a leading international pediatric cancer charity dedicated to some of the most difficult, rare and terminal cases of brain cancer, we wish to extend our support bill **H8329m “Relating to Health and Safety – Terminal Patient’s Right to Try Act”** that is being considered for approval in Rhode Island.

Our charity, composed of 60 chapters, each founded by parents in honor of their child lost to brain cancers like DIPG, DMG, ATRT, ependymoma and medulloblastoma, we uniquely understand that the current regulatory system is inadequate for advancing the innovative therapies we need to take a big step in the cure for cancer. Even despite the adoption of various federal acts like Expanded Access and Right to Try, neither is equipped to deal with terminal, pediatric, and rare cancers. In many ways, our current model forces each patient to fight for themselves and then casually ignores any preliminary data that may help save our children. This creates a “wild west” mentality that not only has ethical problems but overlooks those that don’t have a superior medical team and 3-weeks or more to fight. Left with no options, they are told to go home and make memories while the cancer wins. This is wrong.

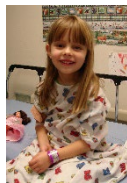
The **Relating to Health and Safety – Terminal Patient’s Right to Try Act**, instead, gives back choice and hope to patients by limiting liability for therapeutic options while balancing the expertise of the treating physician and the rights of the patient. This is precisely what is needed for terminal and rare pediatric cancers where we have no other option.

Since 2018, I have been publicly involved in the effort to open pathways for care for our children, both on an international and federal front. I have spoken in support of similar bills in front of the U.S. Senate, in international forums and throughout various media, hoping for the chance you have before you today. This bill will define Rhode Island as a leader in patient rights in a world that has lost sight of invention, innovation and the value of life and choice for children fighting some of the worst cancers. It is the right thing to do.

Thank you for supporting this vital bill and for prioritizing our children as they fight for their lives. Please let me know how I can help support this process and, as always, we are here to provide additional information as needed to advance this effort.

Sincerely,

Keith Desserich
Chairman, Co-Founder and Father to Elena
keith@thecurestartsnow.org



Elena Desserich, Age 6
Passed from DIPG in 2007

OVER 50 CHAPTERS WORLDWIDE