

Testimony of Ann Ramer
Mother of Lauren and Brent Ramer
HB49 as Introduced by the Governor
House Finance-Health and Human Services Subcommittee
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My name is Ann Ramer. My husband and I have four children, two of which have Li-Fraumeni Syndrome, a rare inherited predisposition to all forms of cancer. Between them, Lauren, aged 14 and Brent, aged 17, have received treatment for six separate cancer diagnoses at Rainbow Babies and Children's Hospital in Cleveland: Adrenal Cancer, Osteosarcoma, PXA grade 2 (brain tumor), metastatic melanoma, AML (an aggressive leukemia which required bone marrow transplant) and finally PXA with anaplasia- (a grade 3 brain cancer). We have been incredibly busy, medically.

There are 40,000 children in the state of Ohio who are served by CMH, each of which have serious health issues like my children. This program began nearly 100 years ago to help children who were stricken with polio. Like those very first families, our afflictions have come upon us quite unexpectedly, and carry complicated long-term side effects. I would ask that this program be preserved as it stands, maintained within the department of health, providing a proven system of care and a crucial safety net for chronically ill children like mine.

Although the proposed language in the Governor's budget seems to "grandfather" our family into the CMH Health program, I am concerned about our future eligibility. But more importantly, I worry about middle class families like mine, who will someday face a devastating diagnosis like cancer without the support of public health nurses and who will be ineligible for financial assistance as medical bills reach the catastrophic maximum. Our family would not qualify for the CMH program if it were transferred to Medicaid as currently proposed at 225% of FPL.

But there are worrisome consequences to consider as this program is phased out. I know that **only** by using CMH approved providers can we have help with our expenses. As I understand the current plan, approximately half of the families have already been moved to Medicaid, weakening the incentive for new providers to enroll, or for existing providers to renew their contract. As more children become medically or financially ineligible, or age out of the program, this will only exacerbate the problem of having adequate services for those who remain. While we might be "grandfathered" into a program, I fear that it will be a much less effective one, with fewer services as enrollment numbers dwindle.

Our family has been ravaged by repeated cancer diagnoses-obviously in physical and emotional terms, but also in financial ones. I recognize that each of you have a responsibility to the state budget. However, never did we have a five year plan in our family budget that involved me living in a hospital for weeks and months on end with our children (at times, with more than one child on the oncology floor), completely

unable to work. Additionally, we have hit annual catastrophic maximum out of pocket expenses, every single year since 2011. By using CMH approved providers whenever possible, we have had some help with these copays. While we remain financially precarious, it is only because of this bit of support that we have been able to stay afloat and in our home.

In addition to help with our co insurance toward the annual catastrophic maximum, which, in our case is currently \$11K, CMH has covered nutritional supplements that are not covered by our insurance at all. As our son Brent has recovered from over 45 surgeries, countless rounds of chemo, and is now dealing with Graft Versus Host Disease, a life threatening side effect from the treatment that cured his leukemia, nutrition has been an ongoing and critical issue. CMH's help in providing these nutritional supplements has been crucial to his health.

The CMH program has been successful in providing support to middle class families with medically fragile children for almost 100 years, enabling parents to remain employed, maintain homeownership, contribute to the economy, pay taxes and most importantly, *maintain private insurance* which pays for the lion's share of medical expenses, in our case- millions of dollars. It is in the interest of the state to continue their support such families with comparatively small bills, and keep the bulk of the cost out of the public system.

In closing, Mr. Chairman and committee members, I would like to thank you for taking the time to listen to our experience and to consider our testimony about Ohio's most medically vulnerable children. These middle- and low-income families struggle with a variety of diagnoses, but all rely on the services that CMH provides in the Department of Health. I would be happy to answer any questions that you might have.