

AS I SEE IT

CHERYL MOZER ON MONEY FOR MEDICAL PROJECTS

RESEARCH INTO CHILD DISEASES
TAKES A BACK SEAT ON FUNDING

Why do people with rare diseases not seem to have any voice in America? If you have a rare disease in America, you cannot count on having a treatment for it because there is no profit to be made. I have no problem with companies making profits, but why don't they "give back" a percentage of that money to help others whose diseases do not have a large enough market to warrant research for a cure?

This year, 12,500 children in the United States will be diagnosed with some type of childhood cancer. Our son survived neuroblastoma cancer, a disease affecting 1 in 10 million children. Half of the children with the late-stage disease that Jacob had do not survive.

None of the treatments Jacob received were approved in children and he was saved only by an experimental antibody therapy found in New York City. Although childhood cancer is the No. 1 cause of death by disease in children (more deaths than all other childhood diseases combined), funding remains consistently low.

A group of seven fathers recently bicycled across America from



Mozer

California to New York (through Kansas City) because there is no funding for the estimated \$3 million to \$5 million it would take to develop a promising proposed treatment.

These fathers were anxiously trying to get the funding for doctors to develop the treatment that could potentially save their children's lives. On top of the normal stress of having a critically ill child, one should not have to bicycle 3,700 miles to raise money for a treatment that could be developed if only the money was there (see www.loneliestroad.org). Private foundations such as Alex's Lemonade Stand Foundation are struggling to make up for the lack of funding.

There are other options that could pay for critical research. Please send e-mail to your state's senators and representatives to urge passage of the bipartisan Conquer Childhood Cancer Act, which would provide funding that could save lives. Twenty

clinical trials are in danger of closing because of a lack of funding, affecting 400 children.

None of the senators in Kansas or Missouri have yet co-sponsored the Conquer Childhood Cancer Act. Reps. Dennis Moore, Nancy Boyda and Jerry Moran of Kansas and Sam Graves and William Lacy Clay of Missouri are co-sponsors, and for this we thank them.

Although the large cancer organizations do great things for adults with cancer, only a tiny percentage of funding goes to research for treating childhood cancer. September was Childhood Cancer Awareness Month, which was largely ignored. If it was your child, neighbor, grandchild, niece or nephew, would this be acceptable?

More information can be accessed at www.curesearch.org. I urge you to send e-mail to your senators and representative today.

Cheryl Mozer is the area coordinator for Alex's Lemonade Stands for Pediatric Cancer Research. (www.alexslimonade.org/KCLEmonade.php). She lives in Blue Springs.