



My name is Jared Hiner, and I am the father of Kamdyn "Kammy" Hiner, resident of Fortville, IN. I would like to first thank you for your time and consideration while reading the following letter about Kammy's Kause, the largest fundraiser for the 4p- Support Group, a 501(c)(3) not-for profit organization. Kammy's Kause is an annual music festival that started in 2004 to raise funds and awareness. To date, we have raised over \$500,000 which has been donated directly to the 4p- Support Group.

4p- and Wolf-Hirschhorn Syndrome (WHS), are extremely rare chromosome disorders which may be suggested by the characteristic facial appearance, growth failure, developmental delays, and seizures. Early intervention such as physical, occupational, and speech therapy have proven to be vital in the development of children with 4p-. There have only been a few hundred cases reported since its discovery in 1967, one of which is my daughter. With so few 4p- children and the lack of funding, new research and information is limited. 4p- is one of the 6,000-8,000 "rare diseases" that affect as many as 30 million people worldwide, 50% of which are children. While Kammy's Kause directly supports the 4p- Support Group our hope is to increase awareness about "rare diseases" in general, they NEED our help to be properly diagnosed.

Shortly after my daughter was diagnosed, we discovered the 4p- Support Group online and joined immediately. The compassion, empathy and knowledge found within the support group helped immensely in the early intervention with Kammy. Not long after joining the group we recognized an enormous need for funding. The annual income for the 4p- Support Group was around \$800 when I first joined, collected via membership fees. After learning this, we organized the first Kammy's Kause and raised \$1,000 for them. What started as an afternoon event with 5 local bands, 50 attendees, and my parents selling candy bars and sodas has grown into an all-day music festival with several local/regional bands, thousands of attendees, Kammy's Ride (motorcycle ride), a big kid zone, our silent auction, food trucks, vendor booths, sponsors while raising more than \$500,000.

The money we raise is used by the 4p- Support Group to host bi-annual national conferences across the United States. It has helped fund research programs and initiatives. It has eliminated membership fees. It has helped ease the burden of travel expenses for 4p families who attend the national conferences. In 2008 money raised from Kammy's Kause was responsible for bringing specialists and doctors from five different countries to our national conference in Washington DC. This was the first time any of those doctors had been together, at the same place, to share information from their own research! At these conferences we can meet up to 100 other families, have one-on-one consultations with the nation's leading 4p- specialists, attend seminars, and receive the support that we families desperately need. In 2012, Indianapolis hosted the 4p- National Conference for the first time in our state's history and the entire conference came to Kammy's Kause to celebrate. That was an incredible experience.

We are very excited to announce that the 18th Annual Kammy's Kause will be held at Landmark Park in Fortville, Indiana on Saturday, August 27th, 2022, and will be a FREE event for the public! With the support of the Town of Fortville, we will be able to raise more money, create more change and give more love than we were able to before. There is something unexplainable that happens within us when we reach out and help someone whose needs are greater than our own; this is the heartbeat of Kammy's Kause.

The continued support from our community is imperative and YOU have the opportunity to create a ripple by supporting the only fundraiser of its kind in the United States, Kammy's Kause.

Follow this link for more information on the diagnosis of Wolf-Hirschhorn Syndrome and 4p- Syndrome
<https://rarediseases.org/rare-diseases/wolf-hirschhorn-syndrome/>

Sincerely,
Jared Hiner
Father, Founder & President

www.kammyskause.org www.4p-supportgroup.org