

Dear Sir or Madam:

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 a music festival started in 2004 to raise funds and awareness for 4p-. To date, we have raised over \$450,000 which has been donated directly to the 4p- Support Group.

**4p-, also known as Wolf-Hirschhorn Syndrome (WHS), is an extremely rare chromosome disorder** which causes mild to severe mental and physical handicaps, organ failure, oral defensiveness, and developmental delays. Early intervention such as physical, occupational, and speech therapy have proven to be vital in the development of children with 4p-. There have been 600+ cases reported since its discovery in the 1960's, thirteen of which are known in Indiana, 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 I discovered the 4p- Support Group online and joined immediately. The compassion, empathy and knowledge found within the support group helped immensly in the early intervention with Kammy. Not long after joining the group though I recognized an enormous need for funding. The annual income for the 4p- Support Group was around \$800 when I first joined. After learning this, I organized the first Kammy's Kause in which raised \$1,000. What started as an afternoon event with 5 local bands, 50 attendees, and my parents selling candy bars and sodas has progressed into an all-day music festival with 14 local bands, thousands of attendees, Kammy's Ride, Kid Zone, Silent AuKtion and sponsors throughout the midwest. It never ceases to amaze me how the bands, volunteers, and families continue to support this event year after year.

In 2008 money raised from Kammy's Kause was solely responsible for bringing specialists and doctors from five different countries to our bi-annual national conference in Washington DC. This was the first time any of these doctors have been together at the same place to share information from their own research! In the past Kammy's Kause has helped several families attend the biannual 4p- National Conference, which is held in different locations across the United States. At these conferences we are able to meet up to 60 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. This year, Indianapolis will once again host the 4p- National Conference!

This summer, Kammy's Kause will celebrate 17 years of restoring hope and transforming lives across the country in way we never could have imagined. The 17<sup>th</sup> Annual Kammy's Kause will be held at Landmark Park in Fortville Indiana on Saturday, July 18th 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.

Sincerely, Jared Hiner

> For more information on 4p-, the 4p- Support Group, and Kammy's Kause please visit the following websites: <u>www.kammykause.org</u> <u>www.4p-supportgroup.org</u> <u>www.facebook.com/kammyskause</u>