



Included with your July newsletter was a flyer for a fundraiser that was being held on behalf of PKS Kids here at the Church on Friday, July 11<sup>th</sup>, from 6 – 10 p.m. I apologize for the fact that there was not an article explaining what that actually means as I have received phone calls asking for an explanation.

PKS Kids™ is a 501(c)3 non-profit organization aimed at helping all people involved with Pallister-Killian Syndrome. Caregivers, family members, friends, teachers and medical professionals can all find help and support here.

Pallister-Killian Mosaic Syndrome or PKS is a congenital disorder caused by chromosome 12p tetrasomy in affected cells resulting in distinct craniofacial features and neurological manifestations. Knowing what PKS means is not nearly as important as understanding the impact that it has on the lives of the children born with this condition. PKS has the following characteristics:

low muscle tone

facial features that are common to the syndrome-high forehead, broad nasal bridge, wide space between the eyes

sparse scalp hair at birth

high, arched palate

hypopigmentation

extra nipples

cognitive and developmental delays. Although most PKS children have these delays, many children are only mildly handicapped.

diaphragmatic hernias

PKS happens randomly and for no known reason. It is thought that there are under 200 diagnosed cases of PKS in the world, however doctors at Children's Hospital in Philadelphia believe that the incidence of PKS is much higher! They feel there may be as many as 2,000 cases in the United States alone. So why aren't these numbers reflected? It is likely that there may be this many cases, but they are going undiagnosed. A main cause for these undiagnosed cases is the method of testing. PKS can be diagnosed in utero via amniocentesis, although occasionally, even this has produced a false negative. After birth, diagnosis is best made by a buccal smear (pronounced "buckle"). It is the painless removal of a sample of cells from the lining of the mouth (inside of the cheek) for study (although a skin biopsy can be as accurate). The blood cells in the body quickly regenerate and the mosaic cells leave the bloodstream after just a few days, making a diagnosis via blood work inconclusive or falsely negative. Parents suspecting that their child might have traits of this syndrome should always ask for a buccal smear.

Consider extending your support to the children and families affected by this disease by attending this fundraiser. You may contact Carol Moran, whose great-granddaughter was pictured on the newsletter flyer, at 462-9101 for further details or to reserve your seat to play Longaberger Bingo. The cost will be \$20 for 20 game sheets with 6 games per sheet. Additional sets of sheets may be purchased for \$10. Raffles and attendance prize will be part of the event.