A medical expense fundraiser event for Justin Hamilton is set for Oct. 28 in Hayes Center.

Justin Hamilton, son of Dave Hamilton of Wauneta and Lesa and Jim Johnson of Hayes Center, was born in 1984 with an extremely rare skin condition called Congenital Erythropoietic Porphyria (CEP).

At birth, doctors knew something was wrong with Justin. At two months old, Justin starting showing signs of skin blisters. By six months old, it was confirmed Justin had CEP through signs of discolored teeth and continued skin blistering which are both common symptoms of the condition.

In most cases, symptoms usually begin soon after birth or in early childhood. The most crucial symptoms that go hand-in-hand with this disorder is skin photosensitivity to the sun that lead to blistering, severe scarring, as well as loss of facial features and possible loss of fingers.

Some other common symptoms of CEP include increased hair growth on sun-exposed skin, brownish-colored teeth, enlarged spleen, bone fragility due to expansion of the bone marrow, vitamin shortage, and shortened life-span of red blood cells.

CEP is the rarest of the eight known types of porphyrias with only several hundred cases reported and is estimated to be a 1 in 1,000,000 chance or less of a person ever getting this disease.

Twenty-eight years ago doctors knew very little about his condition or what could be done.

Growing up, Justin tried his best to keep his skin covered by wearing sun screen, hats, gloves, and long-sleeved shirts.

However, Justin is a lover of animals and the outdoors. Whether it was helping on one of the family farms, hunting, fishing, or high school sports, Justin spent most of his time outside.

Justin, a 2002 Hayes Center High School graduate, was active in football, basketball, track, and FFA.

After high school Justin attended Mid-Plains Community College in North Platte and graduated in 2005 with an Associate Degree in Heating, Ventilation, and Air Conditioning (HVAC).

However, it was difficult for Justin to continue his career in the HVAC field as his scarred hands prevented him from making a closed fist to grab necessary tools in order to work efficiently.

Over the years, Justin has experienced more complications due to the CEP disease. The damage caused to his hands overtime has made simple every day activities more complex as well as coping with increased eye problems.

Family members have researched in depth on CEP and found the best options for Justin's condition.

Family and friends of Justin are working together to raise enough funds to get him needed treatments at the UTMB Porphyria Center in Galveston, Texas.

Possible treatments for CEP include bone marrow transplants and blood transfusions which have reported to be successful in producing normal levels of the enzyme's short supply and reverse the disease symptoms. Gene therapy and stem cell transplantation may be options in the future.

Justin and his wife, Holly (Dack), currently reside outside of Palisade.

The fundraiser is organized by the Night N Gals Committee. Contact one of the members for more information or to help with the event. Members include  Deb Lawson, Amie Broz, Jo Werkmeister and Char Hamilton.