



## **Warsaw, IN**

### **Jingle Bell Run Youth Honoree**

#### **Katherine Alderfer**

It was late May 2010, when Katherine (pictured on the left) was diagnosed with the very rare auto-immune disorder, Juvenile Dermatomyositis (JDM). This disease causes a number of debilitating symptoms including; muscle pain and weakness, ulcers, rash, severe fatigue, lung and heart disorders, calcinosis (muscle hardening) and swallowing and digestive problems. Some children will experience remission, while others will battle the disease their entire life. Medication can help relieve the symptoms, but there is no known cure.

Katherine's symptoms started with a severe rash on her face which then spread to the rest of her body; and she also complained of muscle pain. After a series of doctor visits and blood work Katherine was diagnosed with JDM. Katherine has a wonderful specialist at Riley Hospital for Children in Indianapolis. The road trip is a brutal 2.5 hours each way, but her family feels lucky that they do not have to travel farther away.

Katherine was admitted to the hospital over the Memorial Day weekend in 2010, and spent three days receiving high doses of steroids in an effort to battle her JDM. Progress was slow and in July, 2010 doctors stepped up her treatments. She had surgery to put a port in which helps relieve some of the trauma and makes it easier for her medication to be administered. The disease is different for everyone and her family takes it on a week-by-week basis.

Their lives have changed, but they are making the best of it. Katherine must avoid the sun; which is hard to explain to a six-year old, and her twin sister; especially on hot summer days in Indiana with a pool in the backyard. The family has gotten creative with 8 a.m. bike rides, 4 p.m. swims, jewelry making and moving watching. They are champions at coloring! The days are long but the laughs are plenty with the big "princess" personalities of the girls. Katherine, her twin sister Caroline and the entire family have endured the realities of this disease and have become stronger. Her family describes Katherine as "amazing". We couldn't agree more. The Arthritis Foundation is proud to have Katherine as our 2012 Jingle Bell Run Youth Honoree.

#### **About the Arthritis Foundation**

The Arthritis Foundation ([www.arthritis.org](http://www.arthritis.org)) is committed to raising awareness and reducing the unacceptable impact of arthritis, which strikes one in every five adults and 300,000 children, and is the nation's leading cause of disability. To conquer this painful, debilitating disease, we support education, research, advocacy and other vital programs and services.