

IMMEDIATE RELEASE

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Governor Daugard Proclaims RARE DISEASE DAY in South Dakota to Coincide with National Rare Disease Day Events to be held February 26th, 2011 in Sioux Falls

Sioux Falls, SD – Dennis Daugard, Governor of the state of South Dakota, has issued an Executive Proclamation declaring February 28th, 2010 as RARE DISEASE DAY in South Dakota.

Millions of people around the world will be observing the fourth annual Rare Disease Day on this day. There will be activities across the U.S., throughout Europe, Canada, Australia, China and elsewhere to focus attention on rare diseases as a public health issue.

Here in Sioux Falls, Monarch Cares and Sanford Children's Health Research Center two organizations that support rare disease research and provide families with necessary support will be hosting an opportunity for the public to learn more about rare diseases and the challenges of those affected, while providing those affected the chance to network with others with rare diseases. This event will be held on February 26th, 2010, from 9:30am – 1:00pm at the Sanford Center located at 2301 E 60th Street N, Sioux Falls, SD 57104.

We invite those interested to join us for as we recognize Rare Disease Day in South Dakota. In the United States, a disease is considered rare if it affects fewer than 200,000 Americans. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans. That is nearly 1 in 10 people.

Patients and their families often feel isolated and forgotten, however, there are certain problems and challenges associated with having a rare disease that patients have in common, and Rare Disease Day is intended to focus attention on those needs. Many rare diseases are serious and/or chronic. Many are life-threatening. Even so, people with rare diseases often have trouble accessing the medical or other services they need as those making the decisions are not familiar with their diseases.

Rare Disease Day activities in the U.S. will include a nationwide network of online videos, patient stories and blogs; newspaper, radio and television reports; state and municipal proclamations; and other activities designed to raise awareness of what it means to have a rare disease.

We all know someone with a rare disease. We encourage readers to visit the U.S. Rare Disease Day website (www.rarediseaseday.us) on or before February 28th, 2010, to discover Rare

Disease Day activities in the U.S., and, to visit the global website (www.rarediseaseday.org) to learn what's being done around the world. Please join us for the Sioux Falls, South Dakota, Rare Disease Day event, February 26th, 2010 from 9:30-1:00pm at the Sanford Center. To RSVP, please call 1.800.250.5273 or email RSVP@monarchcares.org and detail how many adults and children will attend.

For more information about the Rare Disease Day on February 26th, 2011, please contact Liz Donohue at liz.donohue@sanfordhealth.org, or Cynthia Wren-Gray at Cynthia@monarchcares.org.