

SR-116, As Adopted by Senate, February 24, 2010

Senators Birkholz, George and Kahn offered the following resolution:

Senate Resolution No. 116.

A resolution recognizing February 28, 2010, as Rare Disease Day in the state of Michigan.

Whereas, February 28 has been recognized as Rare Disease Day by millions of people throughout the United States of America and the world; and

Whereas, According to the National Institutes of Health, nearly 30 million Americans suffer from almost 7,000 rare diseases. Rare diseases are classified as those that affect fewer than 200,000 individuals; and

Whereas, The National Organization for Rare Disorders (NORD), a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them, offers through its website www.rarediseases.org programs of education, advocacy, research, and other services; and

Whereas, Thousands of Michigan residents are affected by rare diseases as patients, friends and family, caregivers, physicians and other medical professionals, providers of social services, and researchers seeking to develop safe and effective treatments; and

Whereas, Since many rare diseases are genetic, about half of the people affected by rare diseases in the United States are children; and

Whereas, People with a rare disease experience challenges due to the nature of their disease, including difficulty in obtaining a timely and accurate diagnosis; difficulty in finding physicians or treatment centers with the needed expertise; treatments that are generally more expensive than those for common diseases; and reimbursement issues related to private insurance, Medicare, and Medicaid; and

Whereas, Research on rare diseases is important because it often adds significantly to the general understanding of more common diseases; now, therefore, be it

Resolved by the Senate, That we hereby recognize February 28, 2010, as Rare Disease Day in the state of Michigan; and be it further

Resolved, That the members of this legislative body urge all Michiganders to use this day as an opportunity to educate themselves about the challenges of rare diseases; and be it further

Resolved, That a copy of this resolution be transmitted to the National Organization for Rare Disorders.