

## A Proclamation to designate May, Fibromuscular Dysplasia Awareness Month

Whereas, Fibromuscular dysplasia (FMD) is a disease that causes abnormal cell growth of the arterial wall. FMD can lead to areas of narrowing (stenosis), beading, aneurysms, and dissections (tears) of the arterial wall; and

Whereas, Until recently there has been very little progress in understanding the disease since it was first diagnosed in 1938. There is still no known cause or cure for the disease and there are no set protocols to treat the disease; and

Whereas, FMD has always been considered and is still classified a rare disease. Many researchers now believe FMD is an under-diagnosed disease. Some of the data suggest that 4-5% of the population may be affected by the disease; and

Whereas, Ninety percent of the patients affected by FMD are women, but men and children also get the disease. There are different classifications of FMD, the two most common types are multi focal and focal fibroplasia. Unlike the adult population, children tend to be diagnosed with focal FMD, which can be more aggressive. Some patients present with both types of the disease. There is no understanding of why there are differences; and

Whereas, Individuals and families affected by fibromuscular dysplasia often experience problems such as a sense of isolation, difficulty in obtaining accurate and timely diagnosis, and optimal treatment options; and

Whereas, Many rare diseases are relatively well-known, but FMD is not well-known by the public or medical community. Patients and their families must bear a large share of the burden for things such as educating others, including their own physicians, and raising funds for awareness and research; and

Whereas, The Fibromuscular Dysplasia Society of America (FMDSA) was founded in March 2003. Over the past 13 years, this association has been active and successful with many programs including public and physician awareness, patient support, and engaging and working with researchers from around the world; and

Whereas, FMDSA is funding the United States Registry for Fibromuscular Dysplasia. Until the recent data was released, it was thought that 75% of FMD cases affected the renal arteries, but that is now known to be inaccurate. It is also very common to have a 5 year delay from onset of symptoms to diagnosis; and

Whereas, There is still much needed awareness and research of the disease. FMD patients present with the same symptoms that much of the general population is affected with, such as hypertension, headaches, and dizziness. Others present with TIA or stroke, dissection (tear) of an artery, aneurysm, swooshing noise in the ear, and renal infarction. Children can present with basic symptoms such as high blood pressure, headaches, insomnia, fatigue, and abdominal pain. Misdiagnoses of FMD can lead to severe consequences and disability; and

Whereas, FMDSA is organizing a global observance of Fibromuscular Dysplasia. During the month of May each year, patients, medical professionals, and researchers, are joining together to focus attention on fibromuscular dysplasia as a public health issue during that month.