SENATE JOINT RESOLUTION
No. 98

STATE OF NEW JERSEY
217th LEGISLATURE

INTRODUCED JANUARY 30, 2017

Sponsorship Updated As Of: 1/9/2018

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SYNOPSIS
Permanently designates April 23, as “Fibrodysplasia Ossificans Progressiva
Awareness Day” in New Jersey.

CURRENT VERSION OF TEXT
As introduced.

(Sponsorship Updated As Of: 1/9/2018)
A Joint Resolution permanently designating April 23 as “Fibrodysplasia Ossificans Progressiva Awareness Day” in New Jersey.

Whereas, Fibrodysplasia Ossificans Progressiva (FOP) is an extremely rare connective tissue disease in which a mutation of the body's repair mechanism causes fibrous tissue, including muscle, tendon, and ligament, to be ossified spontaneously or when damaged, causing joints to become permanently frozen and producing a “second skeleton”; and

Whereas, FOP causes loss of mobility to the affected areas of the body, including the inability to fully open the mouth, limiting speech and eating. Breathing complications can also occur when extra bone formations around the rib cage restrict the expansion of a person’s lungs and diaphragm; and

Whereas, FOP is inherited in an autosomal dominant pattern, which means one copy of the altered gene in each cell is sufficient to cause the disorder, and most cases of FOP result from new mutations in the gene; and

Whereas, The symptoms of FOP usually appear in the first or second decade of life, with the majority of patients diagnosed by the age of 10, depriving children of normal development; and

Whereas, Most children born with FOP tend to have malformed toes or thumbs, which helps distinguish this disorder from other skeletal problems, and a child with FOP will typically develop bones at the neck and on the shoulders, arms, chest area, and feet; and

Whereas, FOP is so rare, it is considered an orphan disease. Since the disease affects so few people, its symptoms are often misdiagnosed as cancer or fibrosis; and

Whereas, Currently there are approximately 200 confirmed cases of FOP in the country, with 12 cases in New Jersey; and

Whereas, There is no cure or approved treatment for FOP. Activities that increase the risk of falling or soft tissue or joint injury should be avoided, as even minor trauma or surgical removal of extra bone growths may provoke additional bone formation; and

Whereas, As a result of limited treatment options, the median age of survival is 40 years with proper management. However, a delayed diagnosis and medical and surgical interventions can decrease life expectancy; and

Whereas, A number of pharmaceutical companies focused on rare disease are currently in varying stages of investigation into different therapeutic approaches for FOP; and

Whereas, Raising public awareness about FOP and the current research being conducted into its causes could encourage the medical community’s continued search for a cure and development of treatment and prevention strategies for this rare genetic disease and other musculoskeletal disorders involving extra-skeletal bone formation; now, therefore,
SJR98 TURNER, WEINBERG

BE IT RESOLVED by the Senate and General Assembly of the State of New Jersey:

1. April 23 shall be permanently designated as “Fibrodysplasia Ossificans Progressiva Awareness Day” in New Jersey in order to raise public awareness about Fibrodysplasia Ossificans Progressiva (FOP) and the current research being conducted into its causes and encourage the medical community’s continued search for a cure and development of treatment and prevention strategies for FOP and other musculoskeletal disorders involving extra-skeletal bone formation.

2. The Governor is respectively requested to annually issue a proclamation recognizing April 23 as “Fibrodysplasia Ossificans Progressiva Awareness Day” in New Jersey, and calling upon public officials and the citizens of this State to observe the day with appropriate activities and programs.

3. This joint resolution shall take effect immediately.

STATEMENT

This resolution permanently designates April 23 as “Fibrodysplasia Ossificans Progressiva Awareness Day” in New Jersey in order to raise public awareness about Fibrodysplasia Ossificans Progressiva (FOP) and the current research being conducted into its causes and encourage the medical community’s continued search for a cure and development of treatment and prevention strategies for FOP and other musculoskeletal disorders involving extra-skeletal bone formation.