
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 335 Session of
2018

INTRODUCED BY BOSCOLA, BROWNE, SCAVELLO, FONTANA, DINNIMAN,
SABATINA, GREENLEAF, MARTIN, RAFFERTY AND COSTA,
APRIL 23, 2018

INTRODUCED AND ADOPTED, APRIL 23, 2018

A RESOLUTION

1 Designating April 23, 2018, as "Fibrodysplasia Ossificans
2 Progressiva Awareness Day" in Pennsylvania.

3 WHEREAS, Fibrodysplasia ossificans progressiva (FOP) is an
4 extremely rare connective tissue disease in which a mutation of
5 the body's repair mechanism causes soft connective tissue,
6 including muscle, tendon and ligament to be ossified
7 spontaneously or when damaged, causing joints to become
8 permanently frozen and producing a "second skeleton"; and

9 WHEREAS, FOP causes loss of mobility to the affected areas of
10 the body, including the inability to fully open the mouth,
11 limiting speech and eating; and

12 WHEREAS, Breathing complications can also occur when extra
13 bone formations around the rib cage restrict the expansion of a
14 person's lungs and diaphragm; and

15 WHEREAS, FOP is inherited in an autosomal dominant pattern,
16 which means one copy of the altered gene in each cell is
17 sufficient to cause the disorder, and most cases of FOP result

1 from new mutations in the gene; and

2 WHEREAS, The symptoms of FOP usually appear in the first or
3 second decade of life, with the majority of patients diagnosed
4 by 10 years of age, depriving children of normal development;
5 and

6 WHEREAS, Most children born with FOP tend to have malformed
7 toes, which helps distinguish this disorder from other skeletal
8 problems, and a child with FOP typically develops extra-skeletal
9 bones at the neck and on the shoulders, arms, chest area, legs
10 and feet; and

11 WHEREAS, FOP is so rare, it is considered an orphan disease;
12 and

13 WHEREAS, Since the disease affects so few people, its
14 symptoms are often misdiagnosed as cancer or fibrosis; and

15 WHEREAS, Currently there are 285 confirmed cases of FOP in
16 the United States; and

17 WHEREAS, In 1991, the FOP Laboratory at the University of
18 Pennsylvania was founded by Eileen Shore, Ph.D., and Frederick
19 Kaplan, M.D., and, in 1997, the Center for Research in FOP and
20 Related Disorders was established by Dr. Kaplan and Dr. Shore;
21 and

22 WHEREAS, There is no cure or approved treatment for FOP; and

23 WHEREAS, Activities that increase the risk of falling or soft
24 tissue or joint injury should be avoided as even minor trauma or
25 surgical removal of extra bone growths may provoke additional
26 bone formation; and

27 WHEREAS, As a result of limited treatment options, the median
28 age of survival is 40 with proper management, but a delayed
29 diagnosis and surgical interventions can worsen FOP; and

30 WHEREAS, A number of pharmaceutical companies focused on rare

1 disease are currently in varying stages of investigation into
2 different therapeutic approaches for FOP; and

3 WHEREAS, Raising public awareness about FOP on the
4 anniversary of the day the FOP gene was discovered in 2006 and
5 about the current research being conducted into its causes could
6 encourage the medical community's continued search for a cure
7 and development of treatment and prevention strategies for this
8 rare genetic disease and other musculoskeletal disorders
9 involving extra-skeletal bone formation; therefore be it

10 RESOLVED, That the Senate designate April 23, 2018, as
11 "Fibrodysplasia Ossificans Prograssiva Awareness Day" in
12 Pennsylvania.