THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 262

Session of 2019

INTRODUCED BY McNEILL, HENNESSEY, SCHLOSSBERG, HEFFLEY, KORTZ, LONGIETTI, NEILSON, KINSEY, HILL-EVANS, HARKINS, FREEMAN, MURT, READSHAW, MILLARD, YOUNGBLOOD, DIGIROLAMO, CALTAGIRONE, SCHWEYER, BURNS AND KULIK, APRIL 25, 2019

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, APRIL 25, 2019

A RESOLUTION

- 1 Recognizing May 19, 2019, as "22q at the Zoo Worldwide Awareness 2 Day" in Pennsylvania.
- 3 WHEREAS, 22q11.2 deletion syndrome, also known as DiGeorge
- 4 syndrome, velo-cardio-facial syndrome and conotruncal anomaly
- 5 face syndrome, among other names, is a congenital defect in
- 6 which a small part of chromosome 22 is missing from the time of
- 7 conception; and
- 8 WHEREAS, 22q11.2 deletion syndrome is the second most
- 9 commonly known chromosomal abnormality, affecting an estimated 1
- 10 in 2,000 to 4,000 live births, yet it is often undiagnosed,
- 11 especially in adults; and
- 12 WHEREAS, Lack of awareness among the public and health care
- 13 professionals indicates there may actually be many more
- 14 individuals affected by this syndrome; and
- 15 WHEREAS, For a parent who has 22q11.2 deletion syndrome, with
- 16 each pregnancy there is a 50% chance of passing a copy of

- 1 chromosome 22 with a small part of that chromosome missing; and
- 2 WHEREAS, The 22q11.2 deletion is most often not inherited
- 3 from either parent and does not usually run in families; and
- 4 WHEREAS, If the condition is suspected, a blood test to
- 5 detect the deletion can be performed; and
- 6 WHEREAS, 22q11.2 deletion syndrome can affect almost every
- 7 system in the body and cause a wide range of health problems;
- 8 and
- 9 WHEREAS, Given the limited scientific studies of this
- 10 syndrome, it is difficult to know how severely a child will be
- 11 affected; and
- 12 WHEREAS, Symptoms of the disorder do not consistently appear
- 13 to be related to the amount of genetic material lost in the
- 14 chromosomal deletion, and therefore, there may be a great deal
- 15 of variation in symptoms among affected individuals; and
- 16 WHEREAS, Common symptoms of the syndrome include heart
- 17 abnormalities, distinctive facial features, recurrent infections
- 18 due to a weakened immune system, gastrointestinal issues and
- 19 kidney problems; and
- 20 WHEREAS, Many children will also experience developmental
- 21 delays, delayed growth and speech and learning disabilities; and
- 22 WHEREAS, While not all symptoms associated with 22q11.2
- 23 deletion syndrome are life-threatening, many children and adults
- 24 affected by the deletion have numerous medical problems during
- 25 their lifetime that may require specialized care; and
- 26 WHEREAS, Although there is no cure for 22q11.2 deletion
- 27 syndrome, there are many therapies and medical interventions
- 28 available to treat the symptoms, and, the earlier that the
- 29 symptoms are detected, the more that doctors can do to help; and
- 30 WHEREAS, Clinical variability, lack of knowledge and the

- 1 unfamiliarity of clinicians with this syndrome all contribute to
- 2 delayed or missed detection, often resulting in avoidable
- 3 medical complications; and
- 4 WHEREAS, Promoting awareness of this complex syndrome among
- 5 the public and the medical community is an important step in
- 6 increasing the likelihood that a correct diagnosis can be made
- 7 early; and
- 8 WHEREAS, "22q at the Zoo Worldwide Awareness Day" is an
- 9 annual event organized and developed by The International
- 10 22q11.2 Foundation aimed at raising the public profile of this
- 11 poorly recognized syndrome; and
- 12 WHEREAS, This event first began in May 2011 in Philadelphia
- 13 and has since evolved into a worldwide phenomenon celebrated
- 14 throughout many countries; and
- WHEREAS, Every year, volunteers, families and friends gather
- 16 at their local zoo, park or backyard to hand out fact sheets,
- 17 play games and show solidarity to those affected by 22q11.2
- 18 deletion syndrome; therefore be it
- 19 RESOLVED, That the House of Representatives recognize May 19,
- 20 2019, as "22q at the Zoo Worldwide Awareness Day" in
- 21 Pennsylvania; and be it further
- 22 RESOLVED, That the House of Representatives acknowledge the
- 23 individuals who participate in "22q at the Zoo Worldwide
- 24 Awareness Day" events and urge its observance throughout this
- 25 Commonwealth for the benefit of all individuals living with
- 26 22q11.2 deletion syndrome and their families.