## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## HOUSE RESOLUTION

No. 937

Session of 2015

INTRODUCED BY HICKERNELL, REED, COHEN, KIRKLAND, BAKER, LONGIETTI, TOOHIL, DUSH, SONNEY, FEE, D. COSTA, VEREB, TOEPEL, HENNESSEY, WARD, CAUSER, ELLIS, MILLARD, HARHART, CUTLER, GIBBONS, ROSS, O'NEILL, MENTZER, NEILSON, A. HARRIS, READSHAW, PAYNE, GOODMAN, WHEELAND, GINGRICH, KINSEY, DONATUCCI, MARSICO, MAJOR, BRADFORD, SAYLOR, ZIMMERMAN, EVERETT, GILLEN, MILNE AND PHILLIPS-HILL, JUNE 20, 2016

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, JUNE 20, 2016

## A RESOLUTION

- Designating the month of July 2016 as "MECP2 Duplication Syndrome Awareness Month" in Pennsylvania.
- 3 WHEREAS, MECP2 duplication syndrome is usually caused by
- 4 duplication of DNA on the Xq28 region of the chromosomes; and
- 5 WHEREAS, MECP2 duplication syndrome is characterized by
- 6 hypotonia, developmental delay, intellectual disability, limited
- 7 or absent speech, constipation, reflux, ataxia, progressive
- 8 spasticity, stereotyped movements of hands, teeth grinding,
- 9 recurrent respiratory infections, epilepsy and developmental
- 10 regression occurring in some boys; and
- 11 WHEREAS, While duplication of MECP2 causes many problems,
- 12 some boys have large duplications that include many other genes,
- 13 and the full extent of phenotypes due to duplication of other
- 14 genes is not completely understood at this time; and
- 15 WHEREAS, Recent studies have shown a link between MECP2

- 1 duplication syndrome and autism, and most boys with this
- 2 syndrome do have distinct features of autism; and
- 3 WHEREAS, Patients with MECP2 duplication syndrome have
- 4 multiple neurological deficits, but, thankfully, their brains
- 5 are not static and are highly responsive to proper stimulation,
- 6 such as schooling, exercise, music, age-appropriate social
- 7 interactions and related activities; and
- 8 WHEREAS, MECP2 duplication syndrome was not formally
- 9 recognized until 2005; and
- 10 WHEREAS, MECP2 duplication syndrome is most commonly
- 11 inherited in an X-linked manner, meaning that affected males
- 12 have, most commonly, inherited the MECP2 duplication from the
- 13 carrier mother, however, spontaneous duplications have been
- 14 reported; and
- 15 WHEREAS, To date, no cases of a father transmitting the
- 16 duplication have been reported; and
- 17 WHEREAS, MECP2 duplication syndrome research, which has shown
- 18 that symptoms of the disorder can be reversed in mice using a
- 19 small antisense oligonucleotide, gives hope that there soon will
- 20 be effective treatments for humans with this disorder; therefore
- 21 be it
- 22 RESOLVED, That the House of Representatives designate the
- 23 month of July 2016 as "MECP2 Duplication Syndrome Awareness
- 24 Month" in Pennsylvania.