

The House Special Committee on Access to Quality Health Care offers the following substitute to HR 590:

A RESOLUTION

1 Creating the House Study Committee on Georgia's Barriers to Access to Adequate Health
2 Care; and for other purposes.

3 WHEREAS, Pediatric Acute-Onset Neuropsychiatric Syndrome ("PANS") and Pediatric
4 Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infection
5 ("PANDAS") create the sudden onset of obsessive-compulsive disorder in children, causing
6 previously healthy and emotionally adjusted children to experience severe anxiety and
7 emotional disturbances; and

8 WHEREAS, children with PANS and PANDAS tend to manifest some of the following
9 symptoms: tics or other abnormal movements, severe separation anxiety, generalized anxiety,
10 irritability, aggression, personality changes, Attention Deficit Hyperactivity Disorder,
11 marked deterioration in learning and school performance, and developmental regression,
12 including regression in handwriting; and

13 WHEREAS, the National Institutes of Mental Health ("NIMH") estimates that 1 in 200
14 children have PANS or PANDAS, meaning these diseases affect roughly 20,000 children in
15 Georgia; and

16 WHEREAS, PANS and PANDAS affect a small subpopulation of patients but have a
17 disproportionately high economic, clinical, and social burden for patients, their caregivers,
18 families, employers, and the health care system; and

19 WHEREAS, children with PANS and PANDAS may experience moderate to dramatic
20 improvement with antibiotics, intravenous immunoglobulin treatment, or plasmapheresis;
21 and

22 WHEREAS, the NIMH suggest that with appropriate early diagnosis and intervention
23 therapies, up to 25-30 percent of childhood mental illnesses may be preventable and may
24 prevent further long-term decline and potentially permanent disability; and

25 WHEREAS, identifying the barriers to PANS and PANDAS—awareness, testing, diagnosis,
26 and early linkage to medication and care—would be in the state's best interest; and

27 WHEREAS, many general pediatricians, nurse practitioners, and pediatric subspecialists are
28 not familiar with the most current diagnostic criteria and treatment guidelines for these
29 disorders; and

30 WHEREAS, in addition to lack of access to treating providers, many insurers do not cover
31 treatment for PANS and PANDAS, which can cost many tens of thousands of dollars,
32 placing it out of reach for most families; and

33 WHEREAS, researchers at the NIMH are currently engaged in extensive research and testing
34 on how to effectively treat PANS and PANDAS; and

35 WHEREAS, researchers at Moleculera Labs at the University of Oklahoma have developed
36 PANS and PANDAS blood testing procedures; and

37 WHEREAS, the University of Arizona and Banner Health System in Arizona have opened
38 the first Centers for Post-Infectious Autoimmune Encephalopathy, providing insurance-based
39 access to expert care and consultative services for general and subspecialist pediatricians
40 around the country; and

41 WHEREAS, the deep medical and bioscience resources in Georgia make our state well
42 situated to meaningfully contribute to best medical practices, research, and medical
43 technology to advance the early diagnosis and treatment of children with PANS and
44 PANDAS; and

45 WHEREAS, the Southeastern PANS/PANDAS Association is a Georgia-based nonprofit
46 organization dedicated to expanding access to expert, insurance-based care for children and
47 families suffering from PANS and PANDAS in our region; and

48 WHEREAS, it is in the state's best interest that there be greater public awareness of this
49 serious health issue among parents, medical providers, and policy makers in Georgia; and

50 WHEREAS, it is imperative to undertake a study of the needs, issues, and problems
51 associated with this disorder; and

52 WHEREAS, it would be beneficial to:

53 (1) Study the benefit of improved awareness and early diagnosis of PANS and PANDAS
54 among medical providers;

55 (2) Examine comprehensive medical and behavioral health services for those suffering
56 from this serious autoimmune disorder which have been demonstrated to have a positive
57 impact on medical outcomes and reduced burdens on patients, families, providers, and
58 society; and

59 (3) Identify barriers to insurance-based care for children with PANS and PANDAS and
60 their families.

61 NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES:

62 (1) **Creation of House study committee.** There is created the House Study Committee
63 on Georgia's Barriers to Access to Adequate Health Care.

64 (2) **Members and officers.** The committee shall be composed of five members of the
65 House of Representatives to be appointed by the Speaker of the House of
66 Representatives. The Speaker shall also appoint an additional three nonlegislative
67 members of the committee as follows: one practicing psychiatrist, one practicing
68 pediatrician, and one public health practitioner. The Speaker shall designate a legislative
69 member of the committee as chairperson of the committee.

70 (3) **Powers and duties.** The committee shall undertake a study of the conditions, needs,
71 issues, and problems mentioned above or related thereto and recommend any action or
72 legislation which the committee deems necessary or appropriate.

73 (4) **Meetings.** The chairperson shall call all meetings of the committee. The committee
74 may conduct such meetings at such places and at such times as it may deem necessary or
75 convenient to enable it to exercise fully and effectively its powers, perform its duties, and
76 accomplish the objectives and purposes of this resolution.

77 (5) **Allowances, expenses, and funding.**

78 (A) The legislative members of the committee shall receive the allowances provided
79 for in Code Section 28-1-8 of the Official Code of Georgia Annotated.

80 (B) Members of the committee who are state officials, other than legislative members,
81 or who are state employees shall receive no compensation for their services on the
82 committee, but they may be reimbursed for expenses incurred by them in the
83 performance of their duties as members of the committee in the same manner as they
84 are reimbursed for expenses in their capacities as state officials or employees.

85 (C) Members of the committee who are not legislators, state officials, or state
86 employees shall receive a daily expense allowance in an amount the same as that
87 specified in subsection (b) of Code Section 45-7-21 of the Official Code of Georgia
88 Annotated, as well as the mileage or transportation allowance authorized for state
89 employees.

90 (D) The allowances authorized by this resolution shall not be received by any member
91 of the committee for more than five days unless additional days are authorized. Funds
92 necessary to carry out the provisions of this resolution shall come from funds
93 appropriated to the House of Representatives; except that funds for the reimbursement
94 of the expenses of state officials, other than legislative members, and for the
95 reimbursement of the expenses of state employees shall come from funds appropriated
96 to or otherwise available to their respective agencies.

97 **(6) Report.**

98 (A) In the event the committee adopts any specific findings or recommendations that
99 include suggestions for proposed legislation, the chairperson shall file a report of the
100 same prior to the date of abolishment specified in this resolution, subject to
101 subparagraph (C) of this paragraph.

102 (B) In the event the committee adopts a report that does not include suggestions for
103 proposed legislation, the chairperson shall file the report, subject to subparagraph (C)
104 of this paragraph.

105 (C) No report shall be filed unless the same has been approved prior to the date of
106 abolishment specified in this resolution by majority vote of a quorum of the committee.
107 A report so approved shall be signed by the chairperson of the committee and filed with
108 the Clerk of the House of Representatives.

109 (D) In the absence of an approved report, the chairperson may file with the Clerk of the
110 House of Representatives a copy of the minutes of the meetings of the committee in lieu
111 thereof.

112 **(7) Abolishment.** The committee shall stand abolished on December 1, 2019.