

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2019

H

1

HOUSE BILL 716

Short Title: Advisory Council for PANS(PANDAS). (Public)

Sponsors: Representatives Murphy and Carney (Primary Sponsors).

For a complete list of sponsors, refer to the North Carolina General Assembly web site.

Referred to: Health, if favorable, Rules, Calendar, and Operations of the House

April 15, 2019

1 A BILL TO BE ENTITLED
2 AN ACT TO ESTABLISH AN ADVISORY COUNCIL ON PEDIATRIC ACUTE-ONSET
3 NEUROPSYCHIATRIC SYNDROME (PANS) AND PEDIATRIC AUTOIMMUNE
4 NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL
5 INFECTIONS (PANDAS).

6 The General Assembly of North Carolina enacts:

7 **SECTION 1.(a)** Article 1B of Chapter 130A of the General Statutes is amended by
8 adding a new section to read:

9 **"§ 130A-33.52. Advisory Council on Pediatric Acute-Onset Neuropsychiatric Syndrome**
10 **(PANS) and Pediatric Autoimmune Neuropsychiatric Disorder associated with**
11 **Streptococcal Infections (PANDAS); membership; terms; compensation;**
12 **meetings; quorum.**

13 (a) There is established the Advisory Council on Pediatric Acute-Onset Neuropsychiatric
14 Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder associated with
15 Streptococcal Infections (PANDAS) within the Department to advise the Governor, the
16 Secretary, and the General Assembly on research, diagnosis, treatment, and education relating to
17 pediatric acute-onset neuropsychiatric syndrome (PANS) and its subset, pediatric autoimmune
18 neuropsychiatric disorder associated with streptococcal infections (PANDAS).

19 (b) Advisory Council Membership.

20 (1) The Secretary shall appoint members to the advisory council as follows,
21 unless otherwise provided:

22 a. A representative of a nonprofit pediatric acute-onset neuropsychiatric
23 syndrome advocacy organization.

24 b. A representative of a professional organization for school
25 psychologists or school social workers organized under the laws of this
26 State.

27 c. An osteopathic professional with experience treating persons with
28 pediatric acute-onset neuropsychiatric syndrome.

29 d. An immunologist licensed and practicing in this State who has
30 experience treating persons with pediatric acute-onset
31 neuropsychiatric syndrome and the use of intravenous
32 immunoglobulin.

33 e. A neurologist licensed and practicing in this State who has experience
34 treating persons with pediatric acute-onset neuropsychiatric
35 syndrome.



- 1 f. A pediatrician licensed and practicing in this State who has experience
2 treating persons with pediatric acute-onset neuropsychiatric
3 syndrome.
- 4 g. A child psychiatrist licensed and practicing in this State who has
5 experience treating persons with pediatric acute-onset
6 neuropsychiatric syndrome.
- 7 h. An employee of the North Carolina Department of Health and Human
8 Services.
- 9 i. A representative of an organization focused on autism.
- 10 j. A nutrition expert with experience treating persons with pediatric
11 acute-onset neuropsychiatric syndrome.
- 12 k. A parent with a child who has been diagnosed with pediatric
13 acute-onset neuropsychiatric syndrome.
- 14 l. A representative of the State Board of Education with experience in
15 special education.
- 16 m. One member of the House of Representatives, appointed by the
17 Speaker of the House.
- 18 n. One member of the Senate, appointed by the President of the Senate.
- 19 (2) The chairs of the Joint Legislative Oversight Committee on Health and Human
20 Services, or the chairs' designees, shall serve on the advisory council. A
21 member of the advisory council who is designated by the chairs of the Joint
22 Legislative Oversight Committee on Health and Human Services may be a
23 member of the General Assembly.
- 24 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,
25 nonvoting member of the advisory council.
- 26 (c) Members appointed under subsection (b) of this section shall serve for a term of three
27 years, and no member shall serve more than two consecutive terms.
- 28 (d) Members of the advisory council shall receive per diem and necessary travel and
29 subsistence expenses in accordance with the provisions of G.S. 138-5 or G.S. 138-6 or travel and
30 subsistence expenses in accordance with the provisions of G.S. 120-3.1, as applicable.
- 31 (e) All administrative support and other services required by the advisory council shall
32 be provided by the Department. Professional support shall be provided by the University of North
33 Carolina School of Medicine.
- 34 (f) The Secretary shall select the chair of the advisory council from among the members
35 of the council.
- 36 (g) The chair shall convene the first meeting of the advisory council no later than October
37 1, 2020. A majority of the council members shall constitute a quorum. A majority vote of a
38 quorum shall be required for any official action of the advisory council. Following the first
39 meeting, the advisory council shall meet upon the call of the chair or upon the request of a
40 majority of council members.
- 41 (h) All vacancies shall be filled by the original appointing officer of the seat that has
42 become vacant within 30 days of the vacancy."

43 **SECTION 1.(b)** Article 1B of Chapter 130A of the General Statutes is amended by
44 adding a new section to read:

45 **"§ 130A-33.53. Advisory Council on Pediatric Acute-Onset Neuropsychiatric Syndrome**
46 **(PANS) and Pediatric Autoimmune Neuropsychiatric Disorder associated with**
47 **Streptococcal Infections (PANDAS); powers and duties; reports.**

48 The advisory council shall have the following powers and duties:

- 49 (1) Advise on coordinating statewide efforts for the study of pediatric acute-onset
50 neuropsychiatric syndrome, and its subset, pediatric autoimmune

- 1 neuropsychiatric disorder associated with streptococcal infections within the
2 State.
- 3 (2) File a report regarding pediatric acute-onset neuropsychiatric syndrome, and
4 its subset pediatric autoimmune neuropsychiatric disorder associated with
5 streptococcal infections to the Secretary, the Governor, and the Joint
6 Legislative Oversight Committee on Health and Human Services on behalf of
7 the General Assembly not later than January 1, 2021, and annually thereafter,
8 on all of the following:
- 9 a. The activities of the advisory council and its findings and
10 recommendations.
- 11 b. Up-to-date practice guidelines for diagnosis and treatment.
- 12 c. Mechanisms to increase clinical awareness and education among
13 physicians, including pediatricians, school-based health centers, and
14 providers of mental health services.
- 15 d. Outreach to educators and parents to increase awareness.
- 16 e. Development of a volunteer expert network to assist in education and
17 outreach."
- 18 **SECTION 2.** This act becomes effective October 1, 2019.