

1 A CONCURRENT RESOLUTION establishing the Kentucky Pediatric
2 Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections
3 (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) Task Force.

4 WHEREAS, pediatric acute-onset neuropsychiatric syndrome (PANS) is a
5 condition possibly caused by abnormal autoimmune or inflammatory response in the
6 brain following any one of various infections in the body, psychological trauma and
7 underlying autoimmune, neurological, endocrine, or metabolic disorders, or other
8 unidentified non-infectious triggers; and

9 WHEREAS, pediatric autoimmune neuropsychiatric disorders associated with
10 streptococcal infections (PANDAS) is a condition that is a subset of PANS that occurs
11 when the associated infection is known to be a strep infection; and

12 WHEREAS, PANDAS and PANS create the sudden onset of obsessive-compulsive
13 disorder in children, causing previously healthy and emotionally adjusted children to
14 experience severe anxiety and emotional disturbances; and

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

20 WHEREAS, the National Institute of Mental Health estimates that one in 200
21 children have PANDAS and PANS, meaning these diseases affect roughly 5,000 children
22 in Kentucky; and

23 WHEREAS, the number of patients with PANDAS is a small portion of those
24 affected by the family of PANS, but those with PANDAS have a disproportionately high
25 economic, clinical, and social burden for patients, their caregivers, families, employers,
26 and the health care system; and

27 WHEREAS, children with PANDAS and PANS may experience moderate to

1 dramatic improvement with antibiotics, intravenous immunoglobulin treatment, or
2 plasmapheresis; and

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

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

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

12 WHEREAS, researchers are currently engaged in extensive research and testing on
13 how to effectively treat PANDAS and PANS; and

14 WHEREAS, it is in the best interest of the Commonwealth that there be greater
15 public awareness of this serious health issue among parents, medical providers, and
16 policy makers, and it is therefore imperative to undertake a study of the needs, issues, and
17 problems associated with this disorder;

18 NOW, THEREFORE,

19 ***Be it resolved by the House of Representatives of the General Assembly of the***
20 ***Commonwealth of Kentucky, the Senate concurring therein:***

21 ➔Section 1. The Legislative Research Commission shall establish the Kentucky
22 Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal
23 Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)
24 Task Force to provide recommendations to the Cabinet for Health and Family Services,
25 health care providers, and the General Assembly on improving research, diagnoses,
26 treatments, and education related to PANDAS and PANS.

27 ➔Section 2. The duties of the task force shall include but are not limited to:

1 (1) Studying the benefits of improved awareness of PANDAS and PANS among
2 parents, educators, and health care providers and early diagnosis of PANDAS and PANS
3 among health care providers;

4 (2) Examining comprehensive medical and behavioral health services for those
5 suffering from this serious autoimmune disorder that have been demonstrated to have a
6 positive impact on medical outcomes and reduced burdens on patients, families,
7 providers, and society; and

8 (3) Identifying barriers to health benefit insurance coverage for care for children
9 with PANDAS and PANS and their families.

10 ➔Section 3. The task force shall be composed of the following members with the
11 final membership of the task force being subject to the consideration and approval of the
12 Legislative Research Commission:

13 (1) Two members of the Senate appointed by the President of the Senate, one of
14 whom shall be designated as co-chair of the task force;

15 (2) One member of the Senate appointed by the Minority Floor Leader of the
16 Senate;

17 (3) Two members of the House of Representatives appointed by the Speaker of
18 the House of Representatives, one of whom shall be appointed by the Speaker of the
19 House of Representatives as co-chair of the task force;

20 (4) One member of the House of Representatives appointed by the Minority Floor
21 Leader of the House of Representatives;

22 (5) The secretary of the Cabinet for Health and Family Services or his or her
23 designee;

24 (6) The commissioner of the Department for Insurance or his or her designee;

25 (7) The commissioner of the Department of Education or his or her designee;

26 (8) One licensed psychiatrist to be selected from a list of three names provided by
27 the Kentucky Medical Association;

1 (9) One licensed pediatrician to be selected from a list of three names provided by
2 the Kentucky Medical Association;

3 (10) One public health practitioner to be selected from a list of three names
4 provided by the Kentucky Public Health Association;

5 (11) One licensed health care provider to be selected from a list of three names
6 provided by the Kentucky Hospital Association;

7 (12) One licensed nurse to be selected from a list of three names provided by the
8 Kentucky Nurses Association;

9 (13) One licensed pharmacist to be selected from a list of three names provided by
10 the Kentucky Pharmacists Association;

11 (14) One licensed psychologist to be selected from a list of three names provided
12 by the Kentucky Psychological Association; and

13 (15) Two parents of children who have been diagnosed with PANDAS and PANS
14 to be selected from a list of three names provided by the Kentucky Medical Association.

15 ➔Section 4. The task force shall meet monthly during the 2020 Interim of the
16 General Assembly. The task force shall submit findings and recommendations to the
17 Legislative Research Commission for referral to the appropriate committee or committees
18 by December 1, 2020.

19 ➔Section 5. Provisions of this Resolution to the contrary notwithstanding, the
20 Legislative Research Commission shall have the authority to alternatively assign the
21 issues identified herein to an interim joint committee or subcommittee thereof, and to
22 designate a study completion date.