

_____ moved to amend as follows:

1 In line 63019, delete "one year" and insert "twenty-four
2 months"

3 In line 63028, delete "The director shall"

4 Delete lines 63029 and 63030

5 In line 63031, after "(D)" delete the balance of the line

6 In line 63032 delete "and at least quarterly thereafter"
7 and insert "Beginning on a date and at intervals determined by
8 the director"

9 In line 63033, after "Parkinsonism" insert "diagnosed on or
10 after the date determined by the director"

11 In line 63045, delete "and"

12 Delete lines 63046 through 63049

13 In line 63050, delete "other information"

14 Delete lines 63064 through 63071

15 Delete lines 63075 through 63080

16 In line 63083, after "confidential" insert "pursuant to
17 section 3701.17 of the Revised Code"; after the underlined
18 period delete the balance of the line

CC0249X3

19 Delete lines 63084 through 63087

20 In line 63097, delete "their" and insert "the department of

21 health's"; delete "in"

22 Delete lines 63098 through 63102

23 In line 63103, delete "conducted"

24 In line 63108, delete "all"

25 In line 63109, delete "individuals" and insert

26 "researchers"

27 In line 63111, after "(1)" delete the balance of the line

28 Delete line 63112

29 In line 63113, delete "(2)"

30 In line 63115, delete "(3)" and insert "(2)"

31 In line 63116, delete "(4)" and insert "(3)"

32 Delete lines 63117 and 63118

33 Delete lines 63128 and 63129

34 In line 63132, after "health" insert "or the director's

35 designee"

36 In line 63144, delete "all" and insert "both"

37 In line 63147, after "(2)" delete the balance of the line

38 Delete lines 63148 through 63157

39 In line 63158, delete "(4)"

40 In line 63159, delete the underlined semicolon

41 Delete lines 63160 through 63162

42 In line 63163, delete all before the underlined period

CC0249X3

43 In line 63164, after "director" insert "or the director's
44 designee"

45 In line 63176, delete "six" and insert "twenty-four"

46 In line 63181, delete "and rates"

47 In line 63186, after the underlined period delete the
48 balance of the line

49 Delete lines 63187 through 63193

50 In line 63194, delete all before the underlined period and
51 insert "The director of health shall describe the registry and
52 provide any information regarding the registry the director
53 deems relevant on the department of health's internet web site"

54 In line 63195, delete "(A)"

55 In line 63196, delete "do all of"

56 Delete line 63197

57 In line 63198, delete "(1) Specify" and insert "specify"

58 In line 63199, delete ", in collaboration with the"

59 Delete line 63200 through 63208

60 In line 63209, delete all before the underlined period

61 The motion was _____ agreed to.

62

SYNOPSIS

63

Parkinson's Disease Registry

64

**R.C. 3701.25, 3701.251, 3701.252, 3701.253, 3701.254, and
65 3701.255**

66

Modifies House-added provisions creating a Parkinson's
67 Disease Registry in the following ways:

68

Data Collection

69

- Changes the timeline for the ODH Director to create the
70 Registry from one year to twenty-four months.

71

- Requires the Director to determine when information is to
72 be reported to the Registry.

73

- Requires only cases of Parkinson's disease or
74 Parkinsonisms diagnosed on or after the date determined by the
75 Director to be reported, as opposed to all cases as required by
76 the House version.

77

- Removes the option for patients to not participate in the
78 Registry.

79

Data access

80

- Removes a provision specifying that a researcher may not
81 contact a patient in the registry if that contact is not
82 coordinated by the Director.

83

- Removes a provision specifying that disclosure of
84 confidential data is only for the stated purpose of the
85 disclosure and is not to be further disclosed.

86

- Requires researchers to obtain approval from ODH's
87 institutional review board (IRB), as opposed to their own
88 institution's IRB as required by the version of the bill passed
89 by the House.

90

- Removes a provision specifying that research must be
91 approved in accordance with federal, state and institutional
92 requirements, although any relevant laws or regulations still
93 apply.

94 - Removes a requirement that the Director maintain records
95 containing the name of the ODH employee who authorized
96 researcher access to Registry data.

97 - Removes a provision specifying that records of data
98 access must be open to public inspection during ODH's normal
99 operating hours, although public records laws still apply.

100 - Removes a provision specifying that a patient must have
101 access to the patient's own data, although laws regarding
102 patient access to data still apply.

103 **Parkinson's Disease Registry Advisory Committee**

104 - Permits the Director to appoint a designee to serve on
105 the Parkinson's Disease Registry Advisory Committee.

106 - Removes a requirement that the Advisory Committee
107 determine what data should be collected.

108 - Removes a requirement that the Advisory Committee conduct
109 a five-year review of the Registry.

110 **Data reporting and publishing**

111 - Removes a requirement that the Director publish the
112 reporting requirements on the Department's website within 30
113 days of the bill's effective date.

114 - Requires the Director to describe the registry and
115 provide any relevant information on ODH's website.

116 - Requires the Director to submit a report to the General
117 Assembly within 24 months of the establishment of the Registry,
118 as opposed to within six months as required by the version of
119 the bill passed by the House.

120 - Removes a requirement that the Director's report include
121 the rates of Parkinson's disease in Ohio by county.

122 - Removes a requirement that the Director create and
123 maintain the Ohio Parkinson's Research Registry web site.

124 - Removes a requirement that the Director include the
125 Registry data in the Ohio Public Health Information Warehouse.

126 **Rulemaking**

127 - Removes a requirement that the Director collaborate with
128 the Advisory Committee when adopting rules.

129 - Removes a requirement that the Director adopt rules
130 regarding procedures for requesting access to data and creating
131 a coding system to remove individually identifying information
132 from Registry data.

133 - Removes a requirement that the Director periodically
134 review and revise data collection requirements to adapt to new
135 knowledge and technologies.