

COMMITTEE ON HEALTH, HOSPITALS AND
HUMAN SERVICES

06/03/15-REPORTED OUT TO THE COMMITTEE ON RULES AND JUDICIARY

BILL NO. 31-0081

Thirty-first Legislature of the Virgin Islands

March 26, 2015

An Act amending title 19 Virgin Islands Code, part V, adding chapter 48 establishing an Autoimmune Disease Registry

PROPOSED BY: Senator Samuel Sanes

1 *Be it enacted by the Legislature of the Virgin Islands:*

2 **SECTION 1.** Title 19, part V of the Virgin Islands Code is amended by adding a
3 new chapter 48 entitled “Autoimmune Disease Registry” to read as follows:

4 **“CHAPTER 48**

5 **§ 1261** As used in this chapter,

6 (a) “Autoimmune disease” means any disease that results from an aberrant
7 immune response, including, without limitation,

8 (1) Acute Disseminated Encephalomyelitis (ADEM)

9 (2) Acute necrotizing hemorrhagic leukoencephalitis

10 (3) Addison’s disease

11 (4) Agammaglobulinemia

12 (5) Alopecia areata

- 1 (6) Amyloidosis
- 2 (7) Ankylosing spondylitis
- 3 (8) Anti-GBM/Anti-TBM nephritis
- 4 (9) Antiphospholipid syndrome (APS)
- 5 (10) Autoimmune angioedema
- 6 (11) Autoimmune aplastic anemia
- 7 (12) Autoimmune dysautonomia
- 8 (13) Autoimmune hepatitis
- 9 (14) Autoimmune hyperlipidemia
- 10 (15) Autoimmune immunodeficiency
- 11 (16) Autoimmune inner ear disease (AIED)
- 12 (17) Autoimmune myocarditis
- 13 (18) Autoimmune oophoritis
- 14 (19) Autoimmune pancreatitis
- 15 (20) Autoimmune retinopathy
- 16 (21) Autoimmune thrombocytopenic purpura (ATP)
- 17 (22) Autoimmune thyroid disease
- 18 (23) Autoimmune urticaria
- 19 (24) Axonal & neuronal neuropathies
- 20 (25) Balo disease
- 21 (26) Behcet's disease
- 22 (27) Bullous pemphigoid
- 23 (28) Cardiomyopathy
- 24 (29) Castleman disease
- 25 (30) Celiac disease
- 26 (31) Chagas disease

- 1 (32) Chronic fatigue syndrome**
- 2 (33) Chronic inflammatory demyelinating polyneuropathy (CIDP)
- 3 (34) Chronic recurrent multifocal osteomyelitis (CRMO)
- 4 (35) Churg-Strauss syndrome
- 5 (36) Cicatricial pemphigoid/benign mucosal pemphigoid
- 6 (37) Crohn's disease
- 7 (38) Cogan's syndrome
- 8 (39) Cold agglutinin disease
- 9 (40) Congenital heart block
- 10 (41) Coxsackie myocarditis
- 11 (42) CREST disease
- 12 (43) Essential mixed cryoglobulinemia
- 13 (44) Demyelinating neuropathies
- 14 (45) Dermatitis herpetiformis
- 15 (46) Dermatomyositis
- 16 (47) Devic's disease (neuromyelitis optica)
- 17 (48) Discoid lupus
- 18 (49) Dressler's syndrome
- 19 (50) Endometriosis
- 20 (51) Eosinophilic esophagitis
- 21 (52) Eosinophilic fasciitis
- 22 (53) Erythema nodosum
- 23 (54) Experimental allergic encephalomyelitis
- 24 (55) Evans syndrome
- 25 (56) Fibromyalgia**
- 26 (57) Fibrosing alveolitis

- 1 (58) Giant cell arteritis (temporal arteritis)
- 2 (59) Giant cell myocarditis
- 3 (60) Glomerulonephritis
- 4 (61) Goodpasture's syndrome
- 5 (62) Granulomatosis with Polyangiitis (GPA) (formerly called Wegener's
- 6 Granulomatosis)
- 7 (63) Graves' disease
- 8 (64) Guillain-Barre syndrome
- 9 (65) Hashimoto's encephalitis
- 10 (66) Hashimoto's thyroiditis
- 11 (67) Hemolytic anemia
- 12 (68) Henoch-Schonlein purpura
- 13 (69) Herpes gestationis
- 14 (70) Hypogammaglobulinemia
- 15 (71) Idiopathic thrombocytopenic purpura (ITP)
- 16 (72) IgA nephropathy
- 17 (73) IgG4-related sclerosing disease
- 18 (74) Immunoregulatory lipoproteins
- 19 (75) Inclusion body myositis
- 20 (76) Interstitial cystitis
- 21 (77) Juvenile arthritis
- 22 (78) Juvenile diabetes (Type 1 diabetes)
- 23 (79) Juvenile myositis
- 24 (80) Kawasaki syndrome
- 25 (81) Lambert-Eaton syndrome
- 26 (82) Leukocytoclastic vasculitis

- 1 (83) Lichen planus
- 2 (84) Lichen sclerosus
- 3 (85) Ligneous conjunctivitis
- 4 (86) Linear IgA disease (LAD)
- 5 (87) Lupus (SLE)
- 6 (88) Lyme disease, chronic
- 7 (89) Meniere's disease
- 8 (90) Microscopic polyangiitis
- 9 (91) Mixed connective tissue disease (MCTD)
- 10 (92) Mooren's ulcer
- 11 (93) Mucha-Habermann disease
- 12 (94) Multiple sclerosis
- 13 (95) Myasthenia gravis
- 14 (96) Myositis
- 15 (97) Narcolepsy
- 16 (98) Neuromyelitis optica (Devic's)
- 17 (99) Neutropenia
- 18 (100) Ocular cicatricial pemphigoid
- 19 (101) Optic neuritis
- 20 (102) Palindromic rheumatism
- 21 (103) PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated
22 with Streptococcus)
- 23 (104) Paraneoplastic cerebellar degeneration
- 24 (105) Paroxysmal nocturnal hemoglobinuria (PNH)
- 25 (106) Parry Romberg syndrome
- 26 (107) Parsonnage-Turner syndrome

- 1 (108) Pars planitis (peripheral uveitis)
- 2 (109) Pemphigus
- 3 (110) Peripheral neuropathy
- 4 (111) Perivenous encephalomyelitis
- 5 (112) Pernicious anemia
- 6 (113) POEMS syndrome
- 7 (114) Polyarteritis nodosa
- 8 (115) Type I, II, & III autoimmune polyglandular syndromes
- 9 (116) Polymyalgia rheumatica
- 10 (117) Polymyositis
- 11 (118) Postmyocardial infarction syndrome
- 12 (119) Postpericardiotomy syndrome
- 13 (120) Progesterone dermatitis
- 14 (121) Primary biliary cirrhosis
- 15 (122) Primary sclerosing cholangitis
- 16 (123) Psoriasis
- 17 (124) Psoriatic arthritis
- 18 (125) Idiopathic pulmonary fibrosis
- 19 (126) Pyoderma gangrenosum
- 20 (127) Pure red cell aplasia
- 21 (128) Raynauds phenomenon
- 22 (129) Reactive Arthritis
- 23 (130) Reflex sympathetic dystrophy
- 24 (131) Reiter's syndrome
- 25 (132) Relapsing polychondritis
- 26 (133) Restless legs syndrome

- 1 (134) Retroperitoneal fibrosis
- 2 (135) Rheumatic fever
- 3 (136) Rheumatoid arthritis
- 4 (137) Sarcoidosis
- 5 (138) Schmidt syndrome
- 6 (139) Scleritis
- 7 (140) Scleroderma
- 8 (141) Sjogren's syndrome
- 9 (142) Sperm & testicular autoimmunity
- 10 (143) Stiff person syndrome
- 11 (144) Subacute bacterial endocarditis (SBE)
- 12 (145) Susac's syndrome
- 13 (146) Sympathetic ophthalmia
- 14 (147) Takayasu's arteritis
- 15 (148) Temporal arteritis/Giant cell arteritis
- 16 (149) Thrombocytopenic purpura (TTP)
- 17 (150) Tolosa-Hunt syndrome
- 18 (151) Transverse myelitis
- 19 (152) Type 1 diabetes
- 20 (153) Ulcerative colitis
- 21 (154) Undifferentiated connective tissue disease (UCTD)
- 22 (155) Uveitis
- 23 (156) Vasculitis
- 24 (157) Vesiculobullous dermatosis
- 25 (158) Vitiligo; and
- 26 (159) Other autoimmune-relegated diseases.

1 (b) 'Individually identifiable health information' means information that is a
2 subset of health information, including demographic information collected from an
3 individual, and:

4 (1) is created or received by a health care provider, health plan, employer, or
5 health care clearinghouse; and

6 (2) relates to the past, present, or future physical or mental health or condition
7 of an individual; the provision of health care to an individual; or the past, present or
8 future payment for the provision of health care to an individual;

9 (3) identifies the individual,

10 (A) by such common identifiers as name, address, birth date, social
11 security number and other common identifies, or

12 (B) with respect to which there is a reasonable basis to believe the
13 information can be used to identify the individual, including

14 **§ 1262.** The Commissioner of the Department of Health shall establish a
15 territory-wide autoimmune disease registry for the purpose of recording types of
16 autoimmune diseases diagnosed or treated in the Virgin Islands and compiling necessary
17 and appropriate information concerning those cases as determined by the Department of
18 Health in order to conduct epidemiologic surveys of autoimmune diseases and to apply to
19 appropriate preventive and control measures. The Department of Health shall adopt
20 regulations and procedures as necessary to carry out the mandates of this chapter.

21 **§ 1263.** Physicians, hospitals, health facilities, ambulatory outpatient surgical
22 centers, and medical laboratories shall report to the Department of Health each confirmed
23 case of autoimmune disease. The Department of Health shall, to the greatest extent
24 possible, use the reported information in the development of the autoimmune disease
25 registry established in section 1262.

1 **§ 1264.** All information reported or collected for the autoimmune disease registry
2 pursuant to this chapter is for use by the Department of Health only, and the Department
3 of Health shall be keep all individually identifiable health information confidential.

4 **§ 1265.** The Department of Health shall grant any person or entity involved in a
5 legitimate research activity access to information concerning autoimmune diseases
6 obtained by the Department of Health under this chapter under the conditions that :

7 (1) No individually identifiable health information is released by the
8 Department of Health and adequate safeguards are put into place to ensure the
9 protection of the identify of each patient whose records will be reviewed;

10 (2) The person or entity conducting the research provides written
11 information about:

12 (A) The purpose of the research project;

13 (B) The nature of the data to be collected and how the research
14 intends to analyze the data; and

15 (C) The records the researcher wishes to review; and

16 (3) An agreement is executed between the Department of Health and
17 the research that specifies the terms of the researcher's use of the records and
18 prohibits the release of any individually identifiable health information
19 inadvertently disclosed by the Department of Health.

20 **§ 1266.** The Department of Health may release confidential information
21 concerning individual autoimmune disease patients to physicians and local health officers
22 for diagnostic and treatment purposes if:

23 (1) The patient's attending physician gives oral or written consent to
24 the release of the information; or

25 (2) The patient gives written consent by completing form authorizing
26 the release of confidential medial information.

