

Information about the Utah Parkinson's Disease Registry

Parkinson's Disease (PD) is a common progressive neurodegenerative disease that is ultimately fatal. It is more common in Utah where the 10-year growth rate of PD in our over-65 population is 31%. Surprisingly, little is known about the causes and treatment of this devastating disease and why the incidence of the disease is increasing so fast in Utah. To learn that information is the purpose of the Utah Parkinson's Disease Registry.

In 2012, a group of business and medical leaders began meeting to discuss the creation of a Parkinson's Disease Registry for the State of Utah. Key members of the group include: Scott Anderson, President and CEO of Zions Bank; renowned scientist Dr. Stefan Pulst, Chair of the Department of Neurology at the University of Utah's School of Medicine; Louis Callister, philanthropist and named partner of the Salt Lake City law firm, Callister, Nebeker & McCullough; and Meghan Holbrook, Trustee of the I. J. and Jeanne Wagner Charitable Foundation.

In 2013, the Utah Legislature passed the Concurrent Resolution on Parkinson's Disease (see attached). Chief Sponsors were Representative Stewart Barlow, MD, and Senator Stuart Adams. The Legislature determined that, in conjunction with the Utah Population Database and the Utah Genome Project, the Utah Parkinson's Disease Registry would be a unique resource to unravel the causes of Parkinson's Disease which affects so many Utah families.

In 2014, because of the Legislature's farsighted Resolution, Zions Bank and the Wagner Foundation each contributed \$100,000 to initially fund the Parkinson's Registry, and the University of Utah donated staff and medical and computer expertise to get the Registry up and running. The Registry is housed at the University of Utah, along with the Utah Cancer Registry and the Utah Autism Registry.

On February 1, 2015, the Utah State Board of Health published a rule that will make Parkinson's Disease a reportable condition in the State of Utah, subject to federal and state privacy laws. This information will enable medical researchers to use the Registry to determine the precise number of PD patients in Utah, study the causes of the disease (and whether the disease may have familial or genetic causes), improve early diagnosis and education, and research and provide proper medical treatment.

Now that the Utah State Board of Health has published its rule, **the Parkinson's Disease Registry is requesting \$200,000 ONE TIME MONEY from this Legislature to make the Registry fully functional.**

1 **CONCURRENT RESOLUTION ON PARKINSON'S DISEASE**

2 2013 GENERAL SESSION

3 STATE OF UTAH

4 **Chief Sponsor: Stewart Barlow**

5 Senate Sponsor: J. Stuart Adams

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7 **LONG TITLE**

8 **General Description:**

9 This concurrent resolution of the Legislature and the Governor urges the Utah
10 Department of Health to add Parkinson's Disease to its registry of diseases.

11 **Highlighted Provisions:**

12 This resolution:

- 13 ▶ urges the Utah Department of Health to include Parkinson's Disease in its registry of
14 diseases; and
- 15 ▶ encourages the Utah Department of Health to consider ways it may partner with
16 interested groups to help fund a Parkinson's Disease registry.

17 **Special Clauses:**

18 None

19

20 *Be it resolved by the Legislature of the state of Utah, the Governor concurring therein:*

21 WHEREAS, Parkinson's Disease (PD) is a common degenerative disease that affects
22 one in 100 individuals over the age of 65;

23 WHEREAS, PD is a progressive, ultimately fatal condition that is more common in
24 Utah than in other states;

25 WHEREAS, on average, PD patients begin to show symptoms from ages 60 to 65;

26 WHEREAS, although the over-65 segment of the United States population is currently
27 growing at a steep 10-year rate of 15%, the growth rate in Utah has reached 31%;

28 WHEREAS, capturing the precise number of PD patients in the state, planning
29 healthcare needs, improving early diagnosis and education, and providing correct medical or

30 surgical therapy will help increase understanding of this disease;

31 WHEREAS, no similar statewide registry covering a population of 2,600,000 exists
32 anywhere in the world;

33 WHEREAS, in conjunction with other state registries, the Utah Population Database,
34 and the Utah Genome Project, this registry could be a unique resource for help in unraveling
35 the causes of this devastating disease;

36 WHEREAS, if established, a PD registry would join a list of other state databases,
37 including the Utah Cancer Registry and the Utah Autism Registry designed to track important
38 diseases and public health hazards;

39 WHEREAS, surprisingly little is known about how common this condition is among
40 different population groups, what the causes are, and whether the patterns of disease are
41 changing over time; and

42 WHEREAS, collecting and analyzing this information in an entire state would provide
43 important clues about the causes of the disease and would help to ensure that adequate health
44 care resources are available for all patients:

45 NOW, THEREFORE, BE IT RESOLVED that the Legislature of the state of Utah, the
46 Governor concurring therein, urges the Utah Department of Health to include Parkinson's
47 Disease in its registry of diseases.

48 BE IT FURTHER RESOLVED that the Legislature and the Governor encourage the
49 Utah Department of Health to consider ways it may partner with interested groups to help fund
50 a Parkinson's Disease registry.

51 BE IT FURTHER RESOLVED that a copy of this resolution be sent to the Utah
52 Department of Health, the Department of Neurology at the University of Utah, and the
53 Parkinson's Disease Association.