## SENATE BILL NO. 782

## 96TH GENERAL ASSEMBLY

INTRODUCED BY SENATOR CURLS.

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TERRY L. SPIELER, Secretary.

## AN ACT

To amend chapter 143, RSMo, by adding thereto one new section relating to designation of tax refunds to the lupus revolving research trust fund.

Be it enacted by the General Assembly of the State of Missouri, as follows:

Section A. Chapter 143, RSMo, is amended by adding thereto one new 2 section, to be known as section 143.1022, to read as follows:

143.1022. 1. For all taxable years beginning on or after January 1, 2012, each individual or corporation entitled to a tax refund in an amount sufficient to make a designation under this section may designate that one dollar or any amount in excess of one dollar on a single return, and two dollars or any amount in excess of two dollars on a combined return, of the refund due be credited to the lupus revolving research trust fund. If any individual or corporation that is not entitled to a tax refund in an amount sufficient to make a designation under this section wishes to make a contribution to the 10 fund, such individual or corporation may, by separate check, draft, or 11 other negotiable instrument, send in with the payment of taxes, or may send in separately, that amount the individual or corporation wishes 12to contribute. Such amounts shall be clearly designated for the fund. 13

2. There is hereby created in the state treasury the "Lupus Revolving Research Trust Fund", which shall consist of money collected under this section. The state treasurer shall be custodian of the fund. In accordance with sections 30.170 and 30.180, the state treasurer may approve disbursements. The fund shall be a dedicated fund and, upon appropriation, money in the fund shall be used solely as provided in this section. Notwithstanding the provisions of section 33.080 to the contrary, any moneys remaining in the fund at the end of the biennium

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22shall not revert to the credit of the general revenue fund. The state treasurer shall invest moneys in the fund in the same manner as other funds are invested. Any interest and moneys earned on such investments shall be credited to the fund. All moneys credited to the 25trust fund shall be considered nonstate funds under section 15, article 26 IV, Constitution of Missouri. The treasurer shall distribute all moneys 27 deposited in the fund at times the treasurer deems appropriate to the 2829 department of health and senior services.

- 3. The director of revenue shall deposit at least monthly all contributions designated by individuals under this section to the state treasurer for deposit to the fund. The director of revenue shall deposit at least monthly all contributions designated by the corporations under this section, less an amount sufficient to cover the costs of collection and handling by the department of revenue, to the state treasury for deposit to the fund. A contribution designated under this section shall only be deposited in the fund after all other claims against the refund from which such contribution is to be made have been satisfied.
- 39 4. (1) There is hereby established in the department of health 40 and senior services a lupus research enhancement program, through which the department shall make grants to state academic medical 42institutions in this state that currently conduct or have an interest in conducting basic and clinical, social, translational, technological, 43 44 epidemiological, and behavioral research on lupus.
  - (2) All research funds shall be awarded on the basis of research priorities established for the program and the scientific merit of the proposed research, as determined by an open, competitive peer review process that ensures objectivity, consistency, and high quality. All investigators, regardless of affiliation, shall have equal access and opportunity to compete for program funds.
  - (3) The peer review process for the selection of research grants awarded under this program shall be modeled generally on the process used by the National Institutes of Health in its grant-making process. Any institution awarded grants shall be awarded such grants for the full cost, both direct and indirect, of conducting the sponsored research consistent with federal guidelines governing all federal research grants and contracts.
    - (4) All intellectual property assets developed under the program

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59 shall be treated in accordance with state and federal law.

- (5) In establishing its research priorities, the department of health and senior services shall consult with the lupus research advisory council created under subsection 5 of this section and consider a broad range of cross-disciplinary lupus research, including but not limited to the following:
  - (a) Research into the cause, cure and diagnosis of lupus;
- (b) Translational and technological research, including research
  to develop improved diagnostic tests;
- 68 (c) Research regarding the cultural, economic, and legal barriers 69 to accessing the health care system for early detection and treatment 70 of lupus; and
- 71 (d) Research examining the health disparities seen in the 72 incidence and prevalence of lupus.
- 5. There is hereby established within the department of health and senior services the "Lupus Research Advisory Council". The members shall be appointed by the director of the department of health and senior services from a list of recommendations by employees of the department and shall consist of the following eight members:
- 78 (1) Four members shall be individuals representing a broad 79 range of expertise and experience in issues relating to lupus;
- 80 (2) One member shall be from the leading lupus advocacy 81 organization dedicated to finding the cause and promoting treatment 82 and awareness:
  - (3) Two members shall be scientists or clinicians with experience with lupus and who participate in various fields of scientific endeavor, including but not limited to the fields of biomedical research, social, translational, behavioral and epidemiological research, and public health; and
- 88 (4) One ex officio member from the department.
- Any individual or organization may also submit nominations to the director for appointment to the council. The director shall appoint a chair from among the members of the council. Of the members first appointed to the council, four shall serve a term of two years and three a term of one year. Thereafter, terms shall be two years. No member shall serve more than two terms. Members shall serve without compensation, but may be reimbursed for actual and necessary

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96 expenses incurred in the performance of their duties. The council shall97 meet at the call of the chair.

- 6. The council shall have the following duties:
- 100 revolving research trust fund created under subsection 2 of this section and make recommendations to the director, who shall at the director's discretion grant approval of applications for grants from the applications recommended by the council. No council member submitting an application for a grant shall review or make any recommendation on such application;
- (2) Consult with the National Institutes of Health, Centers for 106 Disease Control and Prevention, the Agency for Healthcare Research 107and Quality, the Institute of Medicine of the National Academies, lupus 108 advocacy groups such as the Lupus Foundation of America, Inc., and 109 other organizations or entities that may be involved in lupus 110 research. Such consultation shall be to solicit both information 111 regarding current lupus research projects being conducted and 112 113 recommendations for future research projects;
- 114 (3) Submit on or before December thirty-first of each year a 115 report to the general assembly on grants made, grants in progress, 116 program accomplishments, and future program directions. The first report submitted shall include an evaluation and recommendations 117 118 concerning the desirability and feasibility of requiring for-profit grantees to compensate the state in the event that a grant results in the 119 120development of a profit-making product. Such evaluation shall include at least the costs and benefits of requiring a for-profit grantee to repay 121122the grant, to provide the product at cost to state programs serving low-123 income lupus patients, and to pay the state a percentage of the royalties derived from the product. Each report shall include at least 124125 the following information:
- 126 (a) The number and dollar amounts of research grants, including 127 the amount allocated to indirect costs;
  - (b) The subject of research grants;
- 129 (c) A summary of research findings, including discussion of 130 promising new areas; and
- 131 (d) The institutions and campuses receiving grant awards.
- 7. Under section 23.253 of the Missouri sunset act:

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(1) The provisions of the new program and council authorized under this section shall automatically sunset on December thirty-first six years after the effective date of this section unless reauthorized by an act of the general assembly; and

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- 137 (2) If such program is reauthorized, the program authorized 138 under this section shall automatically sunset on December thirty-first 139 twelve years after the effective date of the reauthorization of this 140 section; and
- 141 (3) This section shall terminate on September first of the 142 calendar year immediately following the calendar year in which the 143 program authorized under this section is sunset.

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