

**APPROPRIATIONS REQUEST FORM
OREGON HOUSE DELEGATION
FISCAL YEAR 2010**

DEADLINE FOR SUBMISSION: FEBRUARY 13, 2009

PLEASE NOTE: As required by the House Appropriations Committee, all requests will be made public on the requesting Member's website.

1. Project Title:

Multiple Sclerosis Network and Registry

2. Organization Name and address:

Providence Multiple Sclerosis Center
9427 SW Barnes Rd Suite 595
Portland, OR 97225
(503) 216-1060

3. Primary Contact name, phone number, mobile phone number, fax number and email:

Dr. Stanley Cohan, Director
Providence Multiple Sclerosis Center
(503) 216-1060
stanley.cohan@providence.org

4. Project Location Address (if different from Organization):

The project will establish a network of three clinical care hubs in Oregon to integrate care and resources through out the state. The hubs will be located in Portland, Bend and Medford.

5. Please describe the requesting organization's main activities, and whether it is a public, private non-profit, or private for-profit entity:

Providence Multiple Sclerosis Center cares for more MS patients than any other facility in the state. A team of MS experts, including neurologists, therapists, nurses and researchers offer patients aggressive therapy. The center is a leading participant in regional, national and international clinical trials.

The center is an affiliated partner with the Oregon chapter of the National Multiple Sclerosis Society, bringing more resources to patients and families throughout Oregon.

Providence Cancer Center is part of Providence Health System, a non-profit health care organization operating in the five western states.

Providence Multiple Sclerosis Center and services are located at Providence Portland Medical Center, Providence St. Vincent Medical Center and Providence Milwaukie Hospital. In addition, patients at Providence Hood River, Providence Newberg Hospital, Providence Seaside Hospital and Providence Medford Medical Center have access to Providence Multiple Sclerosis Center services.

6. Briefly describe the activity or project for which funding is requested (please keep to 500 words or less.)

The MS registry is an interactive network of health care professionals for Oregon patients. Researchers, who produced a successful stroke registry that was previously supported by the Oregon Congressional delegation, have provided guidance in the development and implementation of the MS registry. Currently, five clinical care hubs constitute the network; neurologists at the hubs are trained and share up-to-date information on the best practices and treatment to optimize healthcare for MS patients in urban and rural areas. They also help in the recruitment of patients. A special focus will include underserved patients who have limited access to specialized care.

The MS Registry was launched and began patient enrollment and data collection in November 2007. Successful news releases on newspaper, radio, and TV program have documented the project and increased its awareness. The sources of patient recruitment includes the National Multiple Sclerosis Society, several MS centers and neurology practices in Oregon, and online registration on the program website www.providence.org/brain. Since it began, more than 2800 individuals living with MS have signed up to be part of the registry. Data collection from the registry began in November 2007 by the administration of the first survey that collected anonymous health information on disease and treatment history. A second survey has been developed to collect data on demographics, adherence to medication, walking ability, working status, access to medical care and more in-depth family history. Collaborative relationships with network MS centers and neurologists have resulted in the development of common goals to improve the overall care for MS patients in the state.

The program is developing a research proposal on depression and fatigue and how they are associated with physical disability among MS patients. A newly developed web-based applications for MS registry and online MS textbook will go live in 2009.

7. Has this project received federal appropriations funding in past fiscal years?

Yes

7a. If yes, please provide fiscal year, Department, Account, and funding amount of any previous funding.

The MS Registry and Network received \$80,567 in FY08 through the Labor, HHS bill last year and has \$200,000 pending in the FY09 Omnibus bill.

8. Federal agency and account from which funds are requested (Please be specific – e.g. Department of Housing and Urban Development, Economic Development Initiatives account):

Labor, Health and Human Services; Center for Disease Control (CDC) account

9. What is the purpose of the project? Why is it a valuable use of taxpayer funds? How will the project support efforts to improve the economy and create jobs in Oregon?

The incidence of MS in Oregon is among the highest in the US. Unfortunately, there is a severe and ongoing shortage of neurologists in the state who are specifically trained and willing to focus on the treatment of this disease. The problem is particularly acute in the more remote, rural areas. To respond to this medical challenge, the Providence Brain Institute and Multiple Sclerosis Center is taking leadership in the development and implementation of the Oregon Multiple Sclerosis (MS) Network and Registry Project.

- This is first and foremost a humanitarian effort to help patients with a debilitating disease.
- It expands availability of state-of-the-art treatment, combining patient care with new research. No other center in Oregon is currently pursuing this model.
- Oregon patients have more options for treatment locations – especially populations who are traditionally underserved and often must travel long distances for their care.
- There ultimately will be savings to the health care system because earlier diagnosis and treatment can prevent serious disability and loss of employment.
- This program can help pay for itself by keeping people working and not on federal disability, utilizing less testing and careful medication. The net gain: less health care costs per capita for MS treatment.
- The MS Network educates neurologists and other health care professionals regarding the complexity of MS, the nuances of diagnosis, treatment and disease management; and the ongoing need for integrated comprehensive care.
- The MS Network works to provide to all patients, no matter where they live, the best possible medical expertise and educational services.
- The MS Registry collects and analyzes data from patients and physicians to better understand the disease. The research will be used to educate health professionals and develop new treatments.
- An easily accessible online MS treatment guide, written and maintained by the Oregon MS Registry and Network staff, will empower patients and healthcare professionals by providing up-to-date information on diagnosis, treatments, and symptom management in multiple sclerosis.

**10. Have you requested funding for this project from other Members of Congress?
If so, who?**

Yes, we are submitting requests to Senator Wyden, Senator Merkley, Congressman Blumenauer, Congressman DeFazio, Congressman Walden and Congressman Schrader.

11. Funding Details:

a. Total project cost (all funding sources and all years):

\$1,600,000

b. Amount being requested for this project in Fiscal Year 2010:

\$800,000

c. What other funding sources (local, regional, state) are contributing to this project or activity? (Please provide specific dollar amount or percentage.)

The project has received a Biogen grant of \$50,000 and a Teva grant for \$20,570. The project has received 31 private donations totaling \$32,440. The fundraising total for 2008 was \$103,010.

d. Do you expect to request federal funding in future years for this project?

Future requests will be determined based on the success of the FY10 request.

e. Breakdown/budget of the amount you are requesting for this project in FY 2010.

(e.g. salary \$40,000; computer \$3,000):

Items	Description	Salary/Benefits	Travel	Supplies	Contractual	Licensing	Education/ Training	Totals
Project Director		\$150,000						\$150,000
Project Manager	1.0 FTE	\$120,000						\$120,000
Data Analyst	0.5 FTE	\$35,000						\$35,000
Administrative Assistant	0.5 FTE	\$20,000						\$20,000
Data Collection Liaison	0.5 FTE	\$25,000						\$25,000
Network Nurse Educator	0.5 FTE x 3	\$120,000						\$120,000
Network Rehabilitation Educators	0.5 FTE x 3	\$120,000						\$120,000
Grant Writer and Epidemiologist	0.3 FTE	\$45,000						\$45,000
Medical Writer for Website Content	\$50/hr				\$20,000			\$20,000
Website Development and Maintenance					\$70,000			\$70,000
Network Director Meetings	Semi-annually		\$10,000					\$10,000
On-site training for Network Members	\$4,000 x 5 sites						\$20,000	\$20,000
Patient Forums	\$4,000 x 5 sites						\$20,000	\$20,000
Survey & Software Purchasing						\$8,000		\$8,000
Program Pamphlets & Printing				\$7,500				\$7,500
Postage & Office Supplies				\$7,500				\$7,500
Institutional Review Board Fees					\$2,000			\$2,000
Totals		\$635,000	\$10,000	\$15,000	\$92,000	\$8,000	\$40,000	Grand Total:
								\$800,000

f. Please list public or private organizations that have supported/endorsed this project:

Mel Kohn, M.D. MPH
State Epidemiologist
Administrator, Office of Disease Prevention and Epidemiology

Myrna Mulholland
President, Oregon National Multiple Sclerosis Society Oregon Chapter

g. Is this project scalable? (i.e. if partial funding is awarded, will the organization be able to use the funds in FY 2010?):

Yes

**Please return this form no later than February 13, 2009 (via email) to:
appropriations.blumenauer@mail.house.gov**