

region; the Medicare Quality Improvement Organization(s)(QIO(s) serving providers that the proposed regional center aims to serve; state and tribal government entities in the center's geographic service area including, but not limited to, public health agencies; libraries and information centers with health professional and community outreach programs; and consumer/patient organizations.

- As noted below, we propose to give preference to applicants identifying viable sources of matching funds. Viable sources could include grants from states, non-profit foundations, and payment for services from providers able to make such payment. For example, Medicaid providers could choose to contract with a regional center in lieu of a corporate vendor for implementation and meaningful use support services, for which costs are reimbursable under Section 1903 of the Social Security Act, as amended by the HITECH Act. A regional center could also, theoretically, seek to establish itself as a first-choice source of assistance that would realize net retained earnings on service to non-prioritized providers and use those retained earnings as a source of matching funds for its grant-funded activities.

#### *B. Maximum Support Levels Expected To Be Available to Centers Under the Program*

Given current national economic conditions, we propose to exercise the option in the HITECH Act to not require matching funds for awards made in FY 2010. We will encourage use of matching funds and the coordination of existing resources to strengthen proposals for regional centers and potentially expand the number of providers that can be assisted. Review criteria may be established that give preference to proposals including matching funds but that do not automatically preclude otherwise technically meritorious proposals that do not include matching funds.

We propose using ARRA funding for two-year awards made in FY2010 and furnishing providers in awardees' areas with robust support. While we expect the actual ARRA funding awarded per center will vary based on the number and types of providers proposed to be served, and the amount of matching funds proposed by each regional center, we anticipate an average award value on the order of \$1 million to \$2 million per center. The maximum award value we anticipate making available to any one regional center is \$10 million. Funding may also be approximately allocated to

the regional centers in relative proportion to the numbers of prioritized direct assistance recipients identified in the HITECH Act.

#### *C. Procedures To Be Followed by the Applicants*

##### *Timelines*

This notice makes public and invites comments on the draft description of the regional centers program and is not a solicitation of proposals to serve as extension centers under this program. The Federal Government will award funding for the regional centers through a solicitation of proposals, after considering the comments obtained through this notice. The availability of this solicitation will be broadly announced through appropriate and familiar means, including publication in the **Federal Register** of a Notice of the solicitation's availability. This announcement of the solicitation will provide further details on the finalized requirements and application process for regional centers, pursuant to and in compliance with all applicable statutes and regulations, including but not limited to the Paperwork Reduction Act (44 U.S.C. 3501 *et seq.*).

Applicants well prepared to provide robust extension services will likely need at least two months to provide high quality proposals. It is expected, however, that other potential applicants will need more time to prepare proposals.

We propose to make initial awards for regional centers as early as the first quarter of FY2010 and continuing through the fourth quarter of FY2010. Multiple, closely spaced proposal submission dates will be established to allow each geographic area to begin receiving benefit of a regional center as soon as possible. We believe this approach is necessary to allow areas with well prepared applicants to begin work sooner, without excluding from consideration those areas where the best applicants require more time to convene a multi-stakeholder collaboration to develop a robust proposal that includes a viable organizational plan and implementation strategy. We solicit comment on our phased approach to proposal submission dates and issuance of awards.

The target timeframe for awards is intended to enable regional centers to begin supporting provider adoption in time for providers to receive incentive payments with respect to Fiscal Year (hospitals) or Calendar Year (physicians) 2011 and 2012, when potential Medicare incentives are greatest.

#### *D. Comments on Draft Description*

ONC requests comments on this draft description of the regional centers within the Extension Program. Please send comments to the address, for receipt by the due date, specified at the beginning of this notice.

Dated: May 22, 2009.

**Charles P. Friedman,**

*Deputy National Coordinator for Health Information Technology.*

[FR Doc. E9-12419 Filed 5-27-09; 8:45 am]

**BILLING CODE 4150-45-P**

## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Centers for Disease Control and Prevention**

[60Day-0923-09BR]

#### **Proposed Data Collections Submitted for Public Comment and Recommendations**

In compliance with the requirement of Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995 for opportunity for public comment on proposed data collection projects, the Centers for Disease Control and Prevention (CDC) will publish periodic summaries of proposed projects. To request more information on the proposed projects or to obtain a copy of the data collection plans and instruments, call 404-639-5960 and send comments to Maryam I. Daneshvar, CDC Acting Reports Clearance Officer, 1600 Clifton Road, MS-D74, Atlanta, GA 30333 or send an e-mail to [omb@cdc.gov](mailto:omb@cdc.gov).

Comments are invited on: (a) Whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information shall have practical utility; (b) the accuracy of the agency's estimate of the burden of the proposed collection of information; (c) ways to enhance the quality, utility, and clarity of the information to be collected; and (d) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques or other forms of information technology. Written comments should be received within 60 days of this notice.

#### **Proposed Project**

Registration of individuals with Amyotrophic Lateral Sclerosis (ALS) in the National ALS Registry—New—Agency for Toxic Substances and Disease Registry (ATSDR), Coordinating

Center for Environmental Health and Injury Prevention (CCEHIP), Centers for Disease Control and Prevention (CDC).

*Background and Brief Description*

On October 10, 2008, President Bush signed S. 1382: ALS Registry Act which amended the Public Health Service Act to provide for the establishment of an Amyotrophic Lateral Sclerosis (ALS) Registry. The activities described are part of the effort to create the National ALS Registry. The purpose of the registry is to: (1) Better describe the incidence and prevalence of ALS in the United States; (2) examine appropriate factors, such as environmental and occupational, that might be associated with the disease; (3) better outline key demographic factors (such as age, race or ethnicity, gender, and family history) associated with the disease; and (4) better examine the connection between ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS. The registry will collect personal health information that may provide a basis for further scientific studies of potential risks for developing ALS.

During a workshop held by The Agency for Toxic Substances and Disease Registry (ATSDR) in March 2006 to discuss surveillance of selected autoimmune and neurological diseases, it was decided to develop a proposal to build on work that had already been done and coordinate existing datasets to

create a larger database, rather than to start from scratch with medical records review and physician reporting. Four pilot projects were funded to evaluate the accuracy and reliability of existing data from the Center for Medicare and Medicaid Services (CMS) and various datasets from the Veterans Administration. Preliminary results indicate that additional ways to identify cases of ALS will be necessary to increase completeness of the registry. Therefore, ATSDR developed a Web site where individuals will register and will also have the opportunity to provide additional information on such things as occupation, military service, and family history of ALS, which is not available in existing records.

The registration portion of the data collection will be limited to information that can be used to identify an individual to assure that there are not duplicate records for an individual. Avoiding duplication of registrants due to obtaining records from multiple sources is imperative to get accurate estimates of incidence and prevalence, as well as accurate information on demographic characteristics of the cases of ALS.

In addition to questions required for registration, there will be a series of short surveys to collect information on such things as military history, occupations, and family history that would not likely be available from other sources.

This project proposes to collect information on individuals with ALS which can be combined with information obtained from existing sources of information. This combined data will become the National ALS Registry and will be used to provide more accurate estimates of the incidence and prevalence of disease as well as the demographic characteristics of the cases. Information obtained from the surveys will be used to better characterize potential risk factors for ALS which will lead to further in-depth studies.

The existence of the Web site will be advertised by ATSDR and advocacy groups such as the Amyotrophic Lateral Sclerosis Association (ALSA) and the Muscular Dystrophy Association (MDA).

There will be approximately 30,000 individuals living with ALS when the National ALS Registry is initiated, and it is estimated that approximately 25% of those individuals will also participate. In addition, approximately 6,000 people are diagnosed with ALS each year and we expect about one-third of them will participate in the registry. Because an advantage to registration is participating in the surveys, we expect the one time surveys, and the twice yearly survey participation rate will be 50%.

There are no costs to the respondents other than their time.

**ESTIMATED ANNUALIZED BURDEN HOURS**

Data collection instruments/respondents	Number of respondents	Number of responses per respondent	Average burden per response (in hours)	Total burden (in hours)
Validation questions (Screener) for suspected ALS cases .....	6,000	1	2/60	200
Registration Form of ALS cases .....	4,667	1	7/60	544
Cases of ALS completing 1-time surveys .....	2,334	6	5/60	1167
Cases of ALS completing twice yearly surveys .....	2,334	2	5/60	389
<b>Total .....</b>				<b>2300</b>

Dated: May 20, 2009.

**Maryam I. Daneshvar,**

*Acting Reports Clearance Officer, Centers for Disease Control and Prevention.*

[FR Doc. E9-12397 Filed 5-27-09; 8:45 am]

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**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Centers for Disease Control and Prevention**

[60Day-09-0214]

**Proposed Data Collections Submitted for Public Comment and Recommendations**

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Comments are invited on: (a) Whether the proposed collection of information