REPORT OF THE MULTIPLE SCLEROSIS HEALTHCARE ACCESS STUDY COMMITTEE



South Carolina Department of Health and Human Services

January 1, 2009

Multiple Sclerosis Healthcare Access Study Committee

Executive Summary

The goals of the Committee are similar to the goals of the National Multiple Sclerosis Society, to enhance *access to comprehensive, coordinated care* for all patients with MS, regardless of ability to pay. This unifying goal emerged from each of the viewpoints represented among Committee members.

The Committee supports the following 10 goals, which – if achieved – will greatly enhance MS Care in SC:

- 1. There should be three MS Centers in SC, one at the Medical University of SC in Charleston, another at the University of SC in Columbia, and a new, third MS Center at the Greenville Hospital System University Medical Center (GHSUMC) in Greenville.
- 2. Because such comprehensive MS Centers typically operate at a loss, public funding, foundation grants, and philanthropic support should be vigorously pursued, and revenues from MS Center operations (e.g., research, laboratory and imaging services) should be protected.
- **3.** These MS Centers should be capable of providing comprehensive, coordinated MS care of the highest quality.
- 4. All SC MS patients should have access to care at these designated MS Centers, regardless of their insurance status.
- 5. Support for both clinical and research imaging should be sought through various funding agencies to assure access to both clinical and research neuroimaging services at all three SC MS Centers.
- 6. Basic, translational, imaging, and drug-development research projects should be organized by these three MS Centers, in conjunction with other MS Centers in the mid-Atlantic region and Southeast, if possible. An MS Clinical Research Coordinator should be available at each site, and someone should be designated to optimize collaborative efforts across these sites.
- 7. All SC neurologists should be encouraged to maximize the quality of their MS care, and to collaborate with the MS Centers for their own professional/educational benefit, and for the benefit of their patients.

- 8. Funding for MS fellowships should be pursued through available sources, such as the National MS Society, the Consortium of Multiple Sclerosis Centers, and other funding agencies.
- 9. A highly skilled MS Center liaison, with a knowledge of MS like Susan Jordan of the Mid-Atlantic Chapter of the National MS Society, could assure that people with MS and their community-based neurologists are given the best opportunity possible to take full advantage of MS Center resources, and that the MS Centers are taking full advantage of available support and funding sources for MS.
- 10. Whereas the job of MS Center liaison is a high-level position requiring sophisticated knowledge of MS and the agencies interested in MS, "patient care navigators" are recommended to serve as important "grassroots" MS case managers.

Summary of Recommendations:

Multiple Sclerosis affects approximately 4000 people in SC. MS care requires a multidisciplinary team, expensive tests, and even more expensive treatments. The treatment of MS is one of the great success stories in neurology. Nevertheless, many people with MS in SC only get a fraction of the care they need to maximize quality of life, productivity, and to minimize healthcare expenses. The Committee strongly recommends that the SC legislature consider devoting further attention to this important illness. Several philanthropic organizations have been identified that might fund some of the various goals enumerated above, and the Mid-Atlantic Chapter of the National MS Society is willing to help Committee members prepare these applications. The Committee greatly appreciates the interest shown by the South Carolina General Assembly and appropriate state agencies in the problems faced by South Carolinians with MS, and is thankful for the opportunity to share these recommendations.

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Introduction

In 2007, the South Carolina General Assembly passed legislation creating the Multiple Sclerosis Healthcare Access Study Committee, and charged us with studying the availability of health care services to Multiple Sclerosis patients in the state and to report our findings and recommendations back to them by January 1, 2009.

Multiple Sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system (brain and spinal cord). Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. The progress, severity and specific symptoms of MS vary among individuals and are unpredictable. As a result, a definitive diagnosis can take several months to years. No single neurological or laboratory test can confirm or rule out MS.

It is important to note that any Neurologist can treat MS, and more than 90% of people with MS, state that they rely heavily on their neurologist for treatment. However, management of the disease involves multiple healthcare professionals that can include: case managers, specialty pharmacists, physical therapist, occupational therapists, speech language pathologists, neuro-psychologists and others.

In an MS Clinic, having all of these professionals under one roof for "one stop shopping" would be ideal. However, funding (ie., grants, private and or public funding) would have to be identified. From a logistical standpoint, it would seem most cost effective that such a specialized clinic be housed at a "major medical center" or "academic medical center" in South Carolina.

The MS Clinic at the Medical University of South Carolina (MUSC) helps patients to reach maximum independence through medications, clinical trials and rehabilitative treatments. MUSC's multidisciplinary team helps patients manage symptoms, which can include vision problems, muscle weakness, difficulty with coordination, loss of sensation and concentration and memory problems. But even at MUSC's clinic not all disciplines are located in one area.

Prior to July of 2007, MUSC had a waiting list of any where from 4 to 6 months wait for appointments to see new patients. Since that time, the wait time has been reduced and is now considered minimal.

The Committee has identified that there are currently approximately 148 Neurologists practicing in South Carolina, and not all counties have practicing neurologists.

While there is currently no registry to track the number of MS patients in South Carolina, it is estimated that there are approximately 3,800 South Carolinians living with the disease.

REPORT OF THE MULTIPLE SCLEROSIS HEALTHCARE ACCESS STUDY COMMITTEE

Multiple Sclerosis: Enhancing Access to Comprehensive, Coordinated Care for South Carolinians

The MS Access to Care Committee (i.e., the Committee) was created by the South Carolina (SC) legislature to explore mechanisms for enhancing access to Multiple Sclerosis (MS) care for people with MS in South Carolina, and to report the results of this inquiry to the legislature in January 2009. At the most recent Committee meeting, the members discussed recommendations that might enhance the quality of MS care for South Carolinians. The goals of the Committee are similar to the goals of the National Multiple Sclerosis Society, to enhance access to comprehensive, coordinated care for all patients with MS, regardless of ability to pay. This unifying goal emerged from each of the viewpoints represented among Committee members.

Not surprisingly, there are people with MS and patient advocates on the Committee. Patients want their doctors to understand MS, to take the time to understand how MS is affecting so many facets of their lives, and to be prepared to offer assistance as they manage the challenges posed by MS. Patients want to have access to well-trained neurologists, who are experienced and facile with the intricacies of MS, and who are willing to spend the time necessary to get the full picture. Patients want to be properly diagnosed, monitored, and treated. In short, patients want access to comprehensive, coordinated MS care.

In general terms, this means that patients want short waiting times to see MS specialists, they want all the important services to be convenient, and they want to see a physician specializing in MS, rather than just a physician extender. Patients like the idea of three comprehensive MS Centers, one in Greenville, one at the University of South Carolina in Columbia, and the other at MUSC in Charleston. They want the expertise from these comprehensive MS Centers to be available to all MS patients throughout the state, perhaps through telemedicine, satellite clinics, or transportation assistance. Patients want exceptional care for this challenging and complex illness, and they want their neurologists to be as well-informed as possible. Close collaborations between the MS Centers, community-based neurologists, organizations with a special interest in MS, and other healthcare professionals can maximize the chances that their MS care will be the best it can be. Patients may need help identifying their needs and finding resources to satisfy those needs. Access to a Care Coordinator (or "Patient Navigator" as described below) and a Social Worker results in the best outcomes possible. Support from patient advocacy groups should be sought to help recruit, screen and train volunteers, who can also provide valuable support to patients and families struggling to manage MS. These and other recommendations are summarized by the people with MS serving on this committee.

Doctors want what is best for their patients, and their recommendations are similar to those enumerated by people with MS. In general, the physicians on the committee agree that patients with MS should have access to university-based MS Centers where research, education, advanced patient care services, multidisciplinary care teams, and financial/social/psychological support services can be provided "under one roof." In reality, most MS care will be provided by neurologists in the community; such community-based MS care should also be coordinated and comprehensive, so that all of the necessary services are available to patients with MS, whether or not they choose to be evaluated and/or followed in an MS Center. A statewide MS care collaboration is essential to facilitate delivery of comprehensive, coordinated MS care, regardless of the venue where such care is provided. We recommend that the Committee meet quarterly in order to facilitate these important objectives. We recommend that the Committee continue to monitor the organization, distribution, and quality of MS care in SC, and to make recommendations to the SC legislature, appropriate state agencies, and other members of the MS care community in SC. Such recommendations may limit redundancies, promote preventive medicine efforts, and reduce overall MS care costs, while simultaneously improving outcomes and allowing patients to extend their productive work and personal lives.

The Committee supports the following 10 goals, which – if achieved – will greatly enhance MS Care in SC:

- 1. There should be three MS Centers in SC, one at the Medical University of SC in Charleston, another at the University of SC in Columbia, and a new, third MS Center at the Greenville Hospital System University Medical Center (GHSUMC) in Greenville. From an efficiency standpoint, these three MS Centers can serve the large population centers in each of the three main geographic divisions in the state. University-based centers typically have the capacity to allocate resources to such an endeavor with a relatively modest marginal cost, in comparison to a free-standing MS Center. We recommend that these 3 MS Centers seek and maintain membership in the Consortium of MS Centers (CMSC). In addition, some neurology practices may wish to consider membership in the CMSC, and/or certification as an MS clinical site.
- 2. Obtaining financial support for the development and operating costs associated with these three MS Centers is a high priority, as each should offer MS-trained nurses and therapists familiar with the special problems faced by people with MS (e.g., physical therapists, occupational therapists, speech therapists, neuropsychologists, social workers, case managers, etc.). Because such comprehensive MS Centers typically operate at a loss, public funding, foundation grants, and philanthropic support should be vigorously pursued, and revenues from MS Center operations (e.g., research, laboratory and imaging services) should be protected.

- 3. These MS Centers should be capable of providing comprehensive, coordinated MS care of the highest quality. In addition to the services listed above, neurosurgical expertise is needed (e.g., intrathecal baclofen pump implantation). MS-trained nurses are critical for answering phone calls, providing patient education, monitoring medication compliance, coordinating needed care services, and managing the infusion centers that will be needed at each of the three MS Centers. Neuroophthalmology is critical for identifying optic neuritis, which is often the first sign of multiple sclerosis. Neuroradiologists, or neurologists trained to read magnetic resonance images, are necessary for diagnosing, staging, and following the course of MS over time. Physical medicine and rehabilitation specialists are essential, to maximize recovery of function following an MS relapse. Psychiatry and clinical psychology are useful to address the behavioral and emotional difficulties faced by people with MS. Bladder difficulty is very common, and skilled urologists can greatly enhance quality of life, and prevent hospitalizations for urinary tract infection. Many other services could be incorporated into the MS Center, if at all possible "under one roof," so that all of the most important facets of MS care are convenient and readily accessible by all MS Center patients.
- 4. All SC MS patients should have access to care at these designated MS Centers, regardless of their insurance status. Uninsured MS patients should be covered through a grant program, philanthropy, or some other mechanism, and their potential eligibility for available public (or private) health coverage should be examined. All facets of MS care should be covered by this grant program, so that each MS patient gains access to the full range of MS care services.
- 5. All three SC MS Centers should be able to offer state-of-the-art neuroimaging services, including 3 Tesla Magnetic Resonance Imaging (MRI), currently available only in Columbia and Charleston. The addition of a 3 Tesla MRI scanner at GHSUMC would provide comparable clinical and especially research imaging capabilities at all 3 MS Centers. Support for both clinical and research imaging should be sought through various funding agencies to assure access to both clinical and research neuroimaging services at all three SC MS Centers.
- 6. Basic, translational, imaging, and drug-development research projects should be organized by these three MS Centers, in conjunction with other MS Centers in the mid-Atlantic region and Southeast, if possible. The Committee proposes that these MS Centers collaborate with Health Sciences SC (HSSC) (http://www.healthsciencessc.org/) "to improve the health and economic wellbeing of the state through advances in research, education and clinical care." The HSSC collaborative could help the MS Centers develop unified outcome

measures, a state-wide MS database, and other tools to facilitate collaboration among the MS Centers, and between these centers and community-based neurologists. The Committee proposes that a single Institutional Review Board (IRB) should be accepted for MS research projects conducted at any of the three SC MS Centers. For example, any of these three MS Centers could use the HSSC electronic IRB (eIRB) review process, and the other MS Centers (or even affiliated neurology practices) could be covered by the IRB's approval, should they decide to participate in the same study. An MS Clinical Research Coordinator should be available at each site, and someone should be designated to optimize collaborative efforts across these sites.

- 7. All SC neurologists should be encouraged to maximize the quality of their MS care, and to collaborate with the MS Centers for their own professional/educational benefit, and for the benefit of their patients. The Committee recognizes that MS patients will receive most of their MS care locally, often by a neurologist who is highly skilled and experienced in MS care. Nevertheless, a collegial, cooperative relationship between community-based neurologists and those in the MS Centers is of utmost importance. Funding to support collaborations between community neurologists and those at the MS Centers is recommended; for example, such funds could place modern teleconferencing equipment in the MS Centers, and the offices of communitybased neurologists. An educational grant program also should be established to encourage neurologists to stay up to date with MS care. The typical neurologist spends about \$30,000 per month in clinical overhead expenses, and the figure has grown about 50% in the past 8 years, while Medicare reimbursements have declined in real dollars over this period. Thus, a day away from the practice has a huge indirect cost, an opportunity cost (due to lost revenues), and often a direct cost (e.g., paying for travel, lodging, registration fees, and other costs related to an educational activity). While a typical business can build "staff development" costs into its pricing structure, price controls prevent neurologists from doing so. Consequently, neurologists are financially penalized for pursuing educational opportunities that could enhance MS care. A grant program could eliminate this financial penalty and improve MS care quality.
- 8. Funding for MS fellowships should be pursued through available sources, such as the National MS Society, the Consortium of Multiple Sclerosis Centers, and other funding agencies. There are very few MS fellowship training programs in the country. South Carolina has an undersupply of neurologists, including those with expertise in MS. There are certification programs and fellowships available to nurses and physician extenders. MS personnel within neurology practices throughout the state should be encouraged to take advantage of these training programs. A certification program is also available to physical therapists, occupational therapists, speech therapists, and social workers, the Multiple Sclerosis Clinical Specialist certification examination.

- 9. The complexity of MS care requires coordination across multiple organizations, from funding agencies, to MS Centers, to private neurology practices, and patient Funding for an MS Center liaison or consultant is advocacy groups. recommended, to assure that patient care services and metrics are homogeneous across sites, that accurate MS care outcomes are measured, and that patient care quality can be maximized. This MS Center liaison would also work closely with the National MS Society and other patient advocacy groups, and serve as a spokesperson regarding the status of SC's comprehensive, coordinated MS care system. Community-based neurologists and people with MS would be included in educational efforts to raise awareness of the resources available at the three SC MS Centers, including clinical trials and other research opportunities. A highly skilled MS Center liaison, with a knowledge of MS like Susan Jordan of the Mid-Atlantic Chapter of the National MS Society, could assure that people with MS and their community-based neurologists are given the best opportunity possible to take full advantage of MS Center resources, and that the MS Centers are taking full advantage of available support and funding sources for MS.
- 10. Whereas the job of MS Center liaison is a high-level position requiring sophisticated knowledge of MS and the agencies interested in MS, "patient care navigators" are recommended to serve as important "grassroots" MS case managers. The role of a patient care navigator is to maximize the opportunity for optimal MS care for their "clients" with MS. As with other forms of case management, the MS patient care navigator would enhance good outcomes by insuring that patients keep their appointments, by helping them remember what to bring and what to take away from their visits, by informing MS neurologists (and other members of the healthcare team) about current unmet needs. The patient care navigator could participate in data collection efforts so that an accurate, uniform set of outcome measures is collected for all SC MS patients. The patient care navigator would report to the MS Center Liaison, so that the most pressing priorities can be addressed at the state or regional level.

Summary of Recommendations:

Multiple Sclerosis affects approximately 4000 people in SC. MS care requires a multidisciplinary team, expensive tests, and even more expensive treatments. The treatment of MS is one of the great success stories in neurology. Nevertheless, many people with MS in SC only get a fraction of the care they need to maximize quality of life, productivity, and to minimize healthcare expenses. The Committee strongly recommends that the SC legislature consider devoting further attention to this important illness. Several philanthropic organizations have been identified that might fund some of the various goals enumerated above, and the Mid-Atlantic Chapter of the National MS Society is willing to help Committee members prepare these applications. The Committee greatly appreciates the interest shown by the SC legislature and appropriate state agencies in the problems faced by South Carolinians with MS, and is thankful for the opportunity to share these recommendations.

LISTING OF FUNDING SOURCES IDENTIFIED AS POSSIBLE RESOURCES FOR SC MS CENTERS

National Multiple Sclerosis Society

The National MS Society's Health Care Delivery and Policy Research (HCDPR) program studies issues of health care access and quality to improve care for people with MS. The HCDPR program offers multi-year contracts to health services investigators to support projects that address current priorities in the organization, funding, quality, outcomes, and costs of MS care.

Each year, contract requests-for-proposals (RFPs) are distributed, with an invitation to prospective applicants to submit brief letters-of-intent. Letters are screened by an expert, independent peer review committee. On this basis, selected organizations are invited to submit full proposals.

A copy of this year's RFP is available on-line:

http://www.nationalmssociety.org/site/PageServer?pagename=HOM_RES_funding_prog rams, or contact the Vice President of Health Care Delivery and Policy Research at the National Multiple Sclerosis Society. Deadline: Letter of intent due early October, application due early January.

Foundations

The following is a list of possible Foundation funding sources for MS Service Centers in South Carolina. The foundations listed have made grants in South Carolina for health care related activities; information on past grants is included for targeting purposes. Because many donors have restrictions on activity location, the foundations are organized by geographic area.

General SC – no obvious Location restrictions

****** The Fullerton Foundation, Inc. (family foundation)

515 W. Buford St. Gaffney, SC 29341-1703 Telephone: (864) 489-6678 Contact: Walter E. Cavell, Exec. Dir.

Grants for scholarships, medical training, support of a dementia care clinic, an addiction/recovery program, purchased equipment in several grants, supported a post-residency fellowship program at USC in trauma care as a means to address State workforce needs.

Assets: \$49,332,081 Total giving: \$2,131,000 Deadline(s): Apr. 1, Aug. 1 and Dec. 1

*The Springs Close Foundation, Inc.

(formerly Springs Foundation, Inc.) 1826 Second Baxter Crossing Fort Mill, SC 29708-6401 Telephone: (803) 548-2002 Contact: Angela H. McCrae, Pres. Fax: (803) 548-1797 URL: www.thespringsclosefoundation....

Assets: \$41,612,164 Total giving: \$3,092,286 Deadline(s): Mar. 1 and Oct. 1

Health

Grants are made to local programs that support and enhance the quality of life by promoting health and well-being for <u>all</u> segments of the community. No funding for specific health related issues or diseases seen in the recent grants. Did fund the Red Cross, \$2500 for a Juvenile Diabetes research, Keystone (?) outreach program, hospice, Hospitality House, United Way, Lions Club, Pilgrim's Inn (purchased a van), \$11,000 for Parkinson's "Tri County Branch Program", staff development and training for the York County Disability Board.

Joanna Foundation – for small/niche need

P.O. Box 308 Sullivans Island, SC 29482-0308 Telephone: (843) 883-9199 Contact: Margaret P. Schachte, Exec. V.P. E-mail: <u>info@joannafoundation.org</u> URL: <u>www.joannafoundation.org</u>

Small grant size, 1,000 – 15,000 Deadline(s): Jan. 10, May 10, and Sept. 10

Assets: \$4,511,734 Total giving: \$183,500 (much of it small grants – \$1,000, 2,000 or 5,000)

Types of support: Building/renovation, Capital campaigns, General/operating support, Matching/challenge support, Program development. Have given to local AIDS program, Planned Parenthood, much deemed "general support" of projects and programs.

The Self Family Foundation

(formerly The Self Foundation) P.O. Box 1017 Greenwood, SC 29648-1017 Telephone: (864) 941-4011 Contact: Frank J. Wideman III, Pres. Fax: (864) 941-4091 E-mail: <u>info@selffoundation.org</u> URL: www.selffoundation.org

Assets: \$35,711,196 Total giving: \$1,219,670 deadlines, 15th of Feb., May, and Aug., and Nov.

Health & Human Services

Promoting individual and community wellness, prevention and literacy.

Family heritage important..../the future of communities Have helped the Red Cross, paid for blind children to attend camp, United Way and contributions to help with AIDS. Many small (1,000-\$5,000 contributions)

The South Financial Group Foundation

(formerly Carolina First Foundation) M.C. SC968-49 151 Corely Mill Rd. Lexington, SC 29072-7600 Telephone: (803) 996-7406 Contact: G. Bruce Thomas, Exec. Dir. E-mail: <u>bruce.thomas@carolinafirst.com</u> URL: <u>www.thesouthgroup.com/communit...</u>

\$960,550 for 38 grants (high: \$250,000; low: \$5,000) Deadline(s): Quarterly

Program development. The foundation supports organizations involved with arts and culture, health, human services, and community development. Special emphasis is directed toward programs designed to improve education. They give to the United Way, several colleges/universities, and various arts-related causes. Very little done with health care.

The William Bingham Foundation

20325 Center Ridge Rd., Ste. 629 Rocky River, OH 44116-3554 Telephone: (440) 331-6350 Contact: Laura H. Gilbertson, Dir. E-mail: info@WBinghamFoundation.org URL: foundationcenter.org/grantmake...

Assets: \$21,467,662 Total giving: \$1,015,700

Doubtful, while they have done some giving recently in SC, they have never supported anything like a medical specialty center or have focused on any one health condition.

Blue Cross and Blue Shield of South Carolina Foundation

I-20 at Alpine Rd., MC AX-202 Columbia, SC 29219-0001 Contact: Harvey L. Galloway, Exec. Dir. URL: www.bcbsscfoundation.org

Assets: \$91,664,213 Total giving: \$3,192,525

Contributes only to pre-selected organizations. Applications NOT accepted... Board meeting date(s): Spring and Fall

Officers: M. Edward Sellers, Chairperson Judith M. Davis, Secretary Robert A. Leichtle, Treasurer

Directors: Harry Easterling James M. Hart William R. Horton George L. Johnson Joseph Sullivan

Giving primarily for health care and medicine; some support for higher education.

Anderson Area

The Abney Foundation -- Deadline(s): Nov. 15

100 Vine St. Anderson, SC 29621-3265 Telephone: (864) 964-9201 Contact: Carl T. Edwards, Vice-Chair. Fax: (864) 964-9209 E-mail: <u>info@abneyfoundation.org</u> URL: <u>www.abneyfoundation.org</u>

Assets: \$52,921,100 Total giving: \$2,059,163

Keywords: Health Care, medical research, institute, equipment, endowment, research, seed money, fellowships, professorships, internship funds,

Foothills Community Foundation

907 N. Main St. P.O. Box 1228 Anderson, SC 29621-5526 Telephone: (864) 222-9096 Contact: Robert M. Rainey, Pres. Fax: (864) 222-9727 E-mail: <u>rrainey@foothillsfoundation.org</u> URL: www.foothillscommunityfoundati...

Assets: \$12,095,104 Total giving: \$1,833,869

Giving primarily in Abbeville, Anderson, Oconee, and Pickens counties, SC.

The foundation seeks to retain and nurture the charitable wealth of the community for the perpetual benefit of all in the foundation's service area.

Continuing support Scholarship funds

Anmed Health Foundation

800 N. Fant St. Anderson, SC 29621-5708 URL: <u>www.anmedhealth.org</u>

greater Anderson, SC, area. Giving activities include: \$1,609,999 for 2 grants (high: \$1,499,999; low: \$110,000) \$130,657 for foundation-administered programs

In addition to providing indigent medical care, the foundation supports programs that provide developmental therapy for children, mobile medical screenings that reach out to communities, emergency response systems for homebound individuals and enhances the quality health care available in greater Anderson.

The Callie & John Rainey Foundation – Anderson area

402 Boulevard Anderson, SC 29621-4004 Telephone: (864) 222-0804 Contact: John S. Rainey, Chair.

Assets: \$2,857,195 Deadline(s): Sept. 10 Total giving: \$541,718

Giving primarily for the arts, education and to health organizations.

Florence Area

Drs. Bruce and Lee Foundation -

181 E. Evans St. BTC Box 022 Florence, SC 29506-2511 Telephone: (843) 664-2870 Contact: Mr. L. Bradley Callicott, Exec. Dir.

Assets: \$167,537,829 Total giving: \$6,973,900 no deadlines, meet monthly

The foundation aims to advance the welfare of people in the Florence, SC, area, by providing economic support to organizations and programs which contribute to the area's medical, educational, and cultural resources.

Spartanburg Area

The Arkwright Foundation -

314 S. Pine St., Bldg. 100 Spartanburg, SC 29302-2677 Telephone: (864) 585-9213 Contact: Walter S. Montgomery, Jr., Vice-Chair.

Assets: \$16,902,224 Total giving: \$721,922

Giving primarily for education, wildlife conservation, health, social services, the arts, and Protestant education and churches.

Mary Black Foundation, Inc. --

349 E. Main St., Ste. 100 Spartanburg, SC 29302-1985 Telephone: (864) 573-9500 Contact: Philip B. Belcher, Pres. Fax: (864) 573-5805 URL: www.maryblackfoundation.org

Assets: \$87,557,093 Total giving: \$2,585,526

The foundation's mission is to improve the health and wellness of the people and communities of Spartanburg County, SC.

Greenville Area

Community Foundation of Greenville, Inc. – needs to be in the Greenville area

27 Cleveland St., Ste. 101 Greenville, SC 29601-3653 Telephone: (864) 233-5925 Contact: Robert W. Morris, Pres. Fax: (864) 242-9292 E-mail: <u>rmorris@cfgreenville.org</u> URL: <u>www.cfgreenville.org</u>

Assets: \$36,259,519 Total giving: \$4,162,828 Board meeting date(s): Jan., Mar., May, July, Sept., and Nov. Deadline(s): Mar. 6

Conferences/seminars Emergency funds Equipment In-kind gifts Internship funds Matching/challenge support Program development Scholarship funds Seed money Technical assistance

W. W. Burgiss Charities, Inc. – does things in Greenville SC

c/o Wachovia Bank, N.A. 100 N. Main St., 13th Fl. Winston-Salem, NC 27150-6732

Assets: \$2,467,558 Total giving: \$113,000

General/operating support health care. No deadlines.

Columbia Area

First Citizens Foundation, Inc.

1225 Lady St. Columbia, SC 29201-3210 Contact: Peter Bristow, V.P.

Assets: \$10,808,995 Total giving: \$692,450

Giving primarily in SC, with emphasis on Columbia. Initial approach: Contact foundation for application form Deadline(s): None

Equipment General/operating support Program development Scholarship funds Sponsorships

Central Carolina Community Foundation

2711 Middleburg Dr., Ste. 213 Columbia, SC 29204 Telephone: (803) 254-5601 Contact: Dr. Susie H. VanHuss, C.E.O.; For grant application: Joan Fail Hoffman, Dir., Grantmaking and Progs. Fax: (803) 799-6663 E-mail: info@yourfoundation.org URL: www.yourfoundation.org

Assets: \$99,364,342 Total giving: \$6,850,757

Deadline(s): Feb. 15 and Aug. 15 for letter of intent; Apr. 15 and Oct. 15 for full proposal

Giving limited to Calhoun, Clarendon, Fairfield, Kershaw, Lee, Lexington, Newberry, Orangeburg, Richland, Saluda, and Sumter counties, SC. Does health care related giving. An area of special interest is: Organizational Impact Grantmaking Program

Lowcountry Area

Community Foundation of the Lowcountry

(formerly Hilton Head Island Foundation, Inc.) 4 Northridge Dr., Ste. A P.O. Box 23019 Hilton Head Island, SC 29925-3019 Telephone: (843) 681-9100 Contact: Denise K. Spencer, C.E.O. Fax: (843) 681-9101 E-mail: foundation@cf-lowcountry.org URL: www.cf-lowcountry.org

Assets: \$36,909,460 Total giving: \$2,646,026

Board meeting date(s): Jan., Mar., May, July, Sept., and Nov. Deadline(s): Apr. 1, Aug. 1, and Dec. 1

Giving limited to Beaufort, Colleton, Hampton and Jasper counties, SC. Seed Grants

The foundation provides seed grants, designed to stimulate and help launch new programs and projects.

Building/renovation Consulting services Equipment Management development/capacity building Matching/challenge support Program development Scholarships--to individuals Seed money Technical assistance

Coastal Community Foundation of South Carolina

(formerly The Community Foundation Serving Coastal South Carolina) 90 Mary St. Charleston, SC 29403-6230 Telephone: (843) 723-3635 Contact: For grants: Edie Blaskeslee, Sr. Prog. Dir.; George C. Stevens, C.E.O. Fax: (843) 577-3671 E-mail: <u>gstevens@ccfgives.org</u> URL: <u>www.ccfgives.org</u>

Assets: \$126,810,507 Total giving: \$9,621,690

Giving in eight coastal counties of SC: Beaufort, Berkeley, Charleston, Colleton, Dorchester, Georgetown, Hampton and Jasper.

Health care, seed money, program development,

Visit foundation Web site for application forms and additional guidelines per grant type. The foundation's Grants Committee assesses all Open Grants Letters of Intent and then recommends a full proposal be submitted...

APPENDIX I

South Carolina General Assembly

117th Session, 2007-2008

Joint Resolution

Passed by the General Assembly on February 7, 2008 Became law without Governor's signature, February 20, 2008

A JOINT RESOLUTION TO ESTABLISH THE MULTIPLE SCLEROSIS HEALTH CARE ACCESS STUDY COMMITTEE, TO PROVIDE FOR ITS MEMBERS, POWERS, AND DUTIES, AND TO DIRECT THE COMMITTEE TO STUDY THE AVAILABILITY OF HEALTH CARE SERVICES TO MULTIPLE SCLEROSIS PATIENTS IN THIS STATE AND REPORT ITS FINDINGS AND RECOMMENDATIONS TO THE GENERAL ASSEMBLY BY JANUARY 1, 2009, AT WHICH TIME THE STUDY COMMITTEE IS ABOLISHED.

Whereas, the identification and planning of systems to provide service delivery for persons with multiple sclerosis (MS) is vital; and

Whereas, multiple sclerosis is a chronic, unpredictable neurological disease that affects the central nervous system, is varied in frequency and severity of symptoms, and has no cure; and

Whereas, approximately 400,000 Americans acknowledge having MS, and every week about 200 people are diagnosed with the disease. In that there is currently no formal method of tracking the incidence of multiple sclerosis in South Carolina, it is estimated there are more than 3,800 South Carolinians living with MS; and

Whereas, though there is no cure for MS, early diagnosis and specialized treatment are critical to alleviating the symptoms and controlling the progression of MS and improving the function and quality of life of individuals with MS; and

Whereas, although there is a comprehensive MS center affiliated with the Medical University of South Carolina and the Charleston Veteran Affairs Medical Center, South Carolina currently does not have the manpower to meet the substantial needs of patients with MS in the State, and additional MS clinics or centers in other locations, or an expansion of the MUSC MS Center, are needed in order to more adequately meet the needs of individuals with MS; and

Whereas, the average waiting time for a patient to be seen by an MS specialist in South Carolina is six to nine months; and

Whereas, many South Carolina residents must travel great distances, often out of State, in order to obtain specialized health care for the treatment of MS. Now, therefore,

Be it enacted by the General Assembly of the State of South Carolina:

Multiple Sclerosis Health Care Access Study Committee created

SECTION 1. (A) There is created the Multiple Sclerosis Health Care Access Study Committee. This committee shall review the complex needs of persons with multiple sclerosis (MS) in South Carolina and the available resources to meet these needs and shall develop a statewide comprehensive plan for the delivery of coordinated services to persons with MS.

(B) The committee is comprised of:

(1) the director of the Department of Health and Human Services, or a designee, who shall serve as chairman;

(2) the head of the Department of Neurology at the Medical University of South Carolina, or a designee;

(3) the head of the Department of Neurology at the University of South Carolina School of Medicine, or a designee;

(4) the chief executive officer of the South Carolina Medical Association, or a designee;

(5) the president of the South Carolina Hospital Association, or a designee;

(6) an MS nurse specialist upon recommendation by the South Carolina Nurses Association;

(7) a representative of the Mid-Atlantic Chapter of the National Multiple Sclerosis Society;

(8) four persons living with MS, including one from the Low Country, one from the Pee Dee Area, one from the Midlands, and one from the Upstate, upon recommendation of the National Multiple Sclerosis Society, Mid-Atlantic Chapter.

(C) A vacancy on the committee must be filled in the same manner as the original appointment.

(D) Members of the committee shall serve without mileage, per diem, and subsistence.

(E) The Department of Health and Human Services shall provide and coordinate staffing for the study committee.

Plan to be developed for coordinated approach to service delivery

SECTION 2. (A) The committee shall study access to health care services for persons living with MS in this State and develop a specific plan for a coordinated approach to service delivery for persons with MS, using the resources of both the public and private sectors. The plan must include, but is not limited to, an evaluation of how the treatment needs of persons with MS can adequately be met in terms of the level of care and

specialization available; the geographic location of services; and the availability of specialized services.

(B) The committee shall seek consultation from other relevant service providers, including, but not limited to, social work, physical and occupational therapy, and speech and vocational rehabilitation.

(C) In carrying out its responsibilities under this joint resolution, the chairman may appoint subcommittees as he or she considers appropriate. The committee and subcommittees may utilize the knowledge and expertise of any individual in another state agency, group, or association.

(D) The committee shall submit a written report of its findings and recommendations to the General Assembly before January 1, 2009, at which time the committee is abolished.

SECTION 3. This joint resolution takes effect upon approval by the Governor.

Ratified the 13th day of February, 2008.

Became law without the signature of the Governor - 2/20/08.

APPENDIX II

Membership of the Multiple Sclerosis Healthcare Access Study Committee

SC Department of Health and Human Services

Dr. James D. Bradford, Chairman

Medical University of South Carolina

Dr. Nada Abou-Fayssal Department of Neurosciences, Division of Adult Neurology

University of South Carolina School of Medicine

Dr. Davit Mrelashvili USC - School of Medicine

South Carolina Medical Association

Dr. J. E. Carnes South Carolina Neurological Clinic, PA

South Carolina Hospital Association

Dr. Rick Foster, Senior Vice President, Quality and Patient Safety South Carolina Hospital Association

South Carolina Nurses Association

Carolyn P. Jones, RN, MN, MSCN, CRNI 114 Nut Tree Court Lexington, South Carolina 29072

National Multiple Sclerosis Society, Mid-Atlantic Chapter

Susan Jordan, Vice President of Chapter Programs National Multiple Sclerosis Society, Mid-Atlantic Chapter

John R. Absher, MD, FAAN; Absher Neurology; Chair, Clinical Advisory Committee

South Carolina Academy of Physician Assistants:

Mary L. Hewett, MS, PA-C Medical University of South Carolina

Four Persons Living with Multiple Sclerosis

Elizabeth W. Peterson (Low Country)

Debbie Hill (Pee Dee)

Cindy M. Hartman (Midlands)

Clara B. Ziehm (Upstate)