

## Respite Care Case Statement

### Summary

The Amyotrophic Lateral Sclerosis Association Florida Chapter (ALSA – FL) proposes a project that will provide respite care services to Floridians affected by amyotrophic lateral sclerosis (ALS). There currently is no cure for ALS, a disease that causes physical paralysis while leaving the patient's mental functions intact. The cost of the project in FY 2004-2005 will be \$143,292, including \$75,000 paid to contracted health care professionals, and funds for project materials, training, implementation, outreach and coordination.

ALS places extreme physical, emotional and financial burdens on patients and their families. Because ALS patients are fully aware of their helplessness as they lose control of their bodies, they are conscious of the exertion, expense and distress experienced by the loved ones who act as their caregivers. Meanwhile, caregivers push their own bodies, faith and finances to the limit as they strive to add comfort to the last months in the life of a spouse, parent, child or close friend.

Ordinary daily living activities—such as dressing, toileting, bathing and feeding—soon become trials for ALS patients and their caregivers. These activities are made difficult, or impossible, for ALS patients as their paralysis progresses. Caregivers eventually must monitor the patient twenty-four hours a day, seven days a week. In this way, ALS can consume the life of not only the patient, but of loved ones as well. Florida caregivers frequently face desperation, and sometimes contemplate suicide or suffer fatal injuries, while caring for ALS patients.

The only relief from caregiving, prior to hospice, is respite care. Respite care is professional help with the activities of daily living, provided by a Certified Nursing Assistant (CNA) or home health aide. Registered Nurses (RNs) manage and oversee this care, as mandated by Florida law.

Respite care is the sole worry-free break for most ALS caregivers. While the break is usually a short one—about a day per month, often in small hourly increments—caregivers frequently credit it with the preservation of their sanity. In the early stages of paralysis, it can allow the caregiver to continue working to support the patient and other family members. It gives spouses time to send children off to school, or to simply take a much-needed afternoon off.

**ALSA-FL is the only organization in Florida that provides ALS respite care services.**

Medicare, Medicaid, and health insurance almost never cover respite care, and these services are not available from companion, sitter or volunteer services.

ALSA-FL requests support for its free respite care services in order to:

- Educate all new clients and their families (at least 100) about respite care and ALS resources;
- Fund 5,450 hours of emotional and physical respite to 50 ALS patients and their caregivers;
- Provide 12 trainings to 120 home health professionals who will care for ALS patients; and
- Increase awareness of ALS respite care availability in the medical community and in general.

## **History / Background**

ALSA-FL's mission is to find a cure for, and enhance living with, amyotrophic lateral sclerosis. ALS—commonly known as Lou Gehrig's Disease—is poorly understood, difficult to detect and is fatal.

ALS is a neurodegenerative disease that attacks the nerve cells and pathways in the brain and spinal cord, resulting in complete paralysis. The difficulties caused by this disease are especially traumatic for its sufferers and their families. The brain is unaffected as the illness progresses, gradually leaving the ALS patient physically helpless, though fully aware of his or her condition and reliance on loved ones.

ALSA-FL is the Florida Chapter of the national ALSA organization. ALSA-FL's community-based work, supported by local volunteers and contributors, is wholly directed toward making life easier for Floridians with ALS and their families. These services include funding respite care services, coordinating support groups for ALS patients and caregivers, and providing ALS resources to medical professionals and people affected by ALS. In addition, ALSA-FL pursues a cure for ALS by contributing funds that support worldwide, cutting-edge scientific research. Areas of research are selected by the national ALSA organization and are based on its experience, or are generated by scientists devoted to curing ALS who are not affiliated with ALSA. All funds requested for the proposed respite care program will be expended in Florida to benefit ALSA-FL's constituents.

ALSA-FL began as the Tampa Bay Chapter of ALSA, founded in 1987. In 2001, the Tampa Bay Chapter grew and became ALSA's base of operations for the state of Florida, taking on leadership of activities throughout the state, particularly in the Jupiter, West Palm Beach, Ft. Lauderdale, Bradenton and Sarasota areas where most ALSA-FL clients and staff are located.

ALS is rare enough, and its early symptoms are often vague enough, that it takes a year or more to diagnose. Based on Florida's population, there are between 984 and 1,312 people in the state with ALS at any given time (Source: 2001 US Census population estimate / ALS epidemiology study, National Institute of Health, *Mitsumoto, et. al.*, 1998). As Dr. W. G. Bradley of the University of Miami estimates, enough people suffer from ALS that 1 in 200 Floridians have a nuclear family member who has the disease.

Last year, ALSA-FL was aware of, and provided resources to, about 250 patients and their families at any given time. (In 2002, 357 patients were served, but since 105 patients died and 107 new patients sought assistance, about 250 were served at any given time.) The number of diagnosed ALS patients continues to grow as knowledge of the disease spreads: in the first three months of 2003, ALSA-FL began serving 69 new patients, while 19 ALS deaths occurred.

**ALSA-FL is the only statewide organization in Florida that focuses entirely on curing ALS, and on serving patients and their support networks.**

In 2002, ALSA-FL accomplishments include:

- Provision of 3,600 hours of critical respite care funding and services to 33 ALS caregivers. Funds for these services are rarely available from any other source.
- Training 20 home health professionals through in-service programs taught by an RN.
- Formation of new support groups for ALS patients and their caregivers in Gainesville, Ormond/Daytona and Lake Worth, while maintaining groups in nine other areas. (In 2003, new support groups have begun in Melbourne, Sarasota, Weston and Polk County, and additional groups are planned for Orlando, Jacksonville and Tallahassee.)
- Hosting a research symposium in Orlando, featuring three leading scientists from around the world who offered insights to, and answered questions for, ALS patients and families.
- Raising \$190,000 to serve ALS patients through Walks to D'feet ALS events in Tampa, Jupiter, Ft. Lauderdale, Naples and Gainesville with the help of over 1,000 volunteers.
- Continuation of an affiliation with the Tampa Bay Devil Rays pro baseball team by featuring the fourth annual Dine with the Devil Rays fundraiser. The event is coordinated and promoted by players' wives and has raised over \$220,000 since its inception.

### **Statement of Need/Problem Statement**

Because of the progressive paralysis caused by ALS, patients who are past the beginning stage of the disease need a caregiver twenty-four hours a day, seven days a week. This causes a severe problem for patients and their loved ones, who have few community or financial resources to help with full-time home care. The further the disease progresses, the more the patient physically deteriorates. The need for medical care and supervision, and the physical and emotional strain on caregivers, increases in relation to this deterioration.

Since there currently is no effective treatment for ALS, patients generally do not receive all of their long-term care in a hospital. Hospices provide some financial support for home care as patients enter the final stages of the disease, but families usually must share a significant amount of the cost. Most patients die within two years of their ALS diagnosis, but others live with the disease for several years or more. Therefore, most ALS patients require round-the-clock home care for at least a year.

Ironically, there is little funding for home health assistance even though it is much cheaper than having a medical facility care for a patient. Mary Sota of Pasco County discovered this after she had her husband, Vincent, released from a hospital stay. "Upon release, the insurance company, even though it was saving them \$3,000 a day [to keep Vincent out of the hospital], would not give me a CNA or anything," Ms. Sota recalls. Similarly, the insurance company would pay for a home care hoist to lift her husband out of the bed, but not for a wheelchair to put him in after leaving the bed. "My husband was 6' 2"—I'm 5' 2"...but I was going to lift him out of his bed—to where?" she asks. "They would not allow for me to have an electric wheelchair [for Vincent]. He couldn't sit up in a wheelchair and see his children—or go outside."

Although many ALS patients are not at the federal poverty level, they cannot afford to purchase medicine and care at home. One patient shares that he is over income for help from the National Organization of Rare Disorders (NORD) for payment of Rilutek, the only FDA approved

medicine for ALS. Rilutek costs \$900 per month. His household's income is not significant, and his family's insurance cap on prescription drugs is \$3,000 per year. They cannot afford to pay \$10,800 per year for one prescription and continue to pay their bills, and if his wife stops working they will lose their health insurance and will be unable to pay their regular home expenses. He receives a Social Security disability check with is not sufficient to cover all expenses, but is enough to place him beyond the \$665 per month limit for an adult to get Medicaid coverage for prescriptions.

Another man who receives a little less than \$20,000 in disability income is just barely over the income limit for government programs that will help with health care. He and his wife are totally reliant on the disability income because she has stopped working to care for him. He has Medicare and she has no health insurance. They have lost their house and moved into a mobile home.

The agencies that receive government funding to provide general home health care are often too overloaded to serve ALS patients. Most ALS patients referred to these services are placed on waiting lists despite their need for immediate care. For instance, a 49 year-old ALS patient was recently referred by ALSA-FL to a Pinellas County service provider. The patient, a single mother with two disabled teenage sons, was placed on a long waiting list and is currently 300<sup>th</sup> in line to receive services. According to the government program representative, she will not be reached this year for home health care services due to lack of funding. This situation is common among Florida ALS patients.

The Muscular Dystrophy Association (MDA), a nonprofit organization that provides services for persons with about 40 neurological disorders, including ALS, is not providing home health respite to persons with ALS in Florida.

In other states, income taxes frequently pay for health expenses such as those accumulated by ALS patients, but Florida is one of six states that have no income tax. It can cost more than \$200,000 to care for an ALS patient in the advanced stages of the disease. When an ALS patient cannot be cared for in the home due to lack of respite funds, the patient is often hospitalized or placed in a nursing home. Nursing home care, funded by State of Florida Medicaid when the family's resource run out, costs Florida over \$100 per day.

ALS patients rely on family members or close friends for constant care, receiving limited assistance from medical professionals. Often, the physical and emotional strain on patients and caregivers is great, outweighing even the financial burden. One caregiver, a well-educated and capable man with a PhD, admitted to ALSA-FL staff that he was contemplating suicide (a revelation that led him to respite care for his wife, easing his tension). Another caregiver, an elderly gentleman, collapsed and died while bearing the burden of caring for his wife with ALS. A Florida physician diagnosed with ALS actually did commit suicide rather than face the prospect of living with the disease.

These experiences of exhaustion and desperation are not uncommon among patients and their caregivers. Alice Nichols, a Registered Nurse (RN) who works with ALSA-FL patients through Bayada Nurses, describes her observations of one patient's caregiver. "A woman we

admitted...she can't move anything, she is sitting in a wheelchair, and her husband, he is ready to crack," Ms. Nichols says. "We meet her at the mall and we're with her so that she can just have her wheelchair go up and down the mall and look at different things in windows. He can't do that for her, he is ready to leave her...so frustrated with caring for her on a continual basis."

Because the average age at which diagnosis occurs is age 55, caregivers may have their own physical difficulties that add to this strain. It is not highly unusual for the trauma of care to contribute to the illness, collapse or death of an elderly caregiver. Florida is the fourth largest state, has a population growing at more than twice the national average (2.6% in FL), and has a higher percentage of people over age 60 (and over age 65) than any other state (according to the US Administration on Aging). All of these factors mean that Florida is more likely to have ALS patients than national averages indicate, and that caregivers are more likely to be elderly and in need of additional support.

The rareness of ALS adds to the trials faced by caregivers. The average doctor or nurse is not well acquainted with the disease, so that even after diagnosis caregivers are often uninformed or are given misinformation.

Anna Merriman, a Hillsborough County resident, was a caregiver for her mother-in-law, Nellis. "She had a neurologist who was no help at all," Merriman remembers. "I know [with] a lot of illnesses you can't determine the length of time that the patient is going to survive, but at least point us in the right direction as to who we should go to, what is the next step."

Diane Miller, whose husband contracted ALS, says "I really don't recall my doctor ever telling us about it (ALSA-FL), to be honest. Of course at that point everything the doctor said was like such a total shock, because this just wasn't something that we were prepared to hear."

RN Opal Larsen with Health Matters in Hernando County finds that medical staff—especially in a rural setting like hers—are frequently intimidated by the disease. "Before going into home care I worked for 18 years in the recovery room," she explains. "Therefore I was familiar with the ventilator, the feeding tube...so I wasn't afraid of him. A lot of people in the medical field will be."

Caregivers—even professional ones—rely on experts, or other caregivers who have extensive experience, for access to ALS facts, support and resources.

## **Project Description and Objectives**

ALSA-FL's ALS patient and caregiver surveys show that respite care is valued more than any other service except for support groups (also available through ALSA-FL). Respite care—reliable, temporary assistance provided by a home health aide to relieve a caregiver—eases the strain on those caring for ALS patients. It gives patients' primary caregivers a rare and valuable opportunity to get help, or to simply take a few hours off. It provides an additional outlet for ALS patients, who rarely receive new visitors. In addition, it forges a connection between ALS caregivers, a private agency RN and an ALSA-FL Patient Services Coordinator, ensuring that ALS patients get help accessing the resources they need.

ALSA-FL provides respite care funds that are used by patients' caregivers to employ professional medical home care services not covered by Medicare, Medicaid or private insurance. ALSA-FL provided \$38,063 in respite care funds to 33 families last year. The average respite care funds per family equaled \$1,570. The grants ranged from \$245 to \$3,600 per family, varying according to each family's need and length of care. Most families received about \$250 per month, which generally provides compensation for 20 to 30 hours of care.

While this level of service is significant, ALSA-FL is currently unable to provide respite care funds to all of the families who badly need it. There is sometimes a waiting list for this financial aid. At other times, when families' respite contracts are up for renewal, funding must be reduced by ALSA-FL due to lack of additional funds. In other cases, extra hours of respite care are justified but cannot be afforded.

To increase its level of respite care services, ALSA-FL seeks support toward the achievement of the following objectives in 2004:

- Educate all new ALS clients and their families (at least 100) about respite benefits, hiring respite providers, ALS resources and appropriate ALS care practices.
- Fund 5,450 hours of emotional and physical respite to 50 ALS patients and their caregivers;
- Provide 12 trainings to 120 home health professionals who lack experience with, and information about, the care of patients with ALS; and
- Increase awareness of respite care availability in the medical community and in the community in general through ALSA-FL mailings and marketing activities.

## **Methods**

### *Outreach and Project Intake*

ALSA-FL staff members regularly contact, or visit with, medical providers, to raise their awareness of the organization and the resources it provides to patients. This will be an area of emphasis in 2004. Information about ALSA-FL resources will be sent by mail to at least 200 physicians, and to Florida home health agencies, hospital discharge planners and hospices. Staff will also continue to attend health fairs and visit health fairs, assisted living facilities, hospitals and nursing homes.

Usually, the person in need of services finds ALSA-FL on the Internet, or finds a listing for ALSA-FL in the phone book or newspaper. This first contact is often made because a caregiver is seeking help and is relatively unfamiliar with services and resources available to ALS patients.

To reach out to patients and their families, ALSA-FL publicizes its efforts on an ongoing basis and reaches out to new patients through its existing network of supporters. Referrals to ALSA-FL are provided by hospices, clinics, home health agencies, hospital discharge planners, the Florida Respite Coalition's Respite Locator Service and others. ALSA-FL has convinced at least 10 major television stations in Florida to air public service announcements, produced by the national ALSA organization and featuring celebrity Bob Costas, which educate the public about ALS. ALSA-FL has produced its own public service announcement, with ALSA-FL

spokesperson and major league baseball umpire Phil Cuzzi, which is also featured on TV stations throughout the state.

### *Assessment and Caregiver Education*

All new ALS patients and caregivers who contact ALSA-FL will be educated about the respite care program and other appropriate ALS resources. This education will be done in person, via support groups or by phone, depending on the situation and the needs of clients.

As part of this process, ALSA-FL Patient Services Coordinator or Respite Care Program Director assesses the situation of the ALS patient and any caregivers. For instance, the staff person asks about the patient's type of ALS (onsets vary), disease progression and means of financial support.

The assessment process is designed to respond to patient and caregiver needs. The caregiver, usually a family member, is an active participant in this process. The caregiver plays a lead role in articulating which services are needed. The Patient Services Coordinator helps the caregiver formulate a Care Management Plan that is unique to the patient. This plan states which ALS services and resources are needed, either through ALSA-FL, one of its collaborators, or another agency. If respite care is among the identified needs, the coordinator begins preparations to provide this service through ALSA-FL.

### *Provision of Respite Care Services*

Before respite care begins, there are often concerns or barriers to care that ALSA-FL must address. For instance, caregivers may feel guilty about leaving their loved one with another person, even for a very short time. In addition, the ALS patient may feel uneasy about having a respite care provider help with certain tasks, such as bathing. Or, there may be uneasiness about letting the respite care provider into the house while no other family members are present. There are safety issues to consider, because at a certain point it is no longer safe for a patient to be left even briefly unattended. Respite care, in general, is a new concept for most people that must be fully explained by the coordinator and accepted by the patient's family.

Once the family has a need for respite care, the process can move quickly. ALSA-FL helps the family find a home health aide through an agency, or the family finds one on its own. Families fill out brief applications and legal forms that clarify they are responsible for monitoring the quality of care received from the provider. Once a suitable aide is found, the coordinator helps negotiate the best pay rate. ALSA-FL and the caregiver sign an agreement stating that ALSA-FL will cover all or part of the respite cost. The usual rate paid to the provider is \$14 an hour, but ALSA-FL has helped negotiate rates as low as \$7.50 per hour during the past year.

Before the aide begins providing care, an RN evaluates the situation in the home (in accordance with Florida law) and signs an agreement between the family and the agency. The RN also checks in with the family and with ALSA-FL at least once a month to monitor respite care on an ongoing basis. RN Opal Larsen explains that the "purpose is to make sure that the CNA [Certified Nursing Assistant] is doing what they're supposed to do...but I have to tell you that it rarely, if ever, is limited to that."

Larsen uses Mary Sota's husband Vincent as an example. "We sent a gentleman in because Vince was surrounded by women all of the time. And even though he wasn't verbal—he communicated through blinking his eyes or through eye movement—we sent a male CNA in there who would just talk to him the entire time. And so when the CNA went in, he'd say 'how about this one game on Sunday,' or 'that one play, they should have done this'.... He was the perfect CNA for Vince...and that was one of the best emotional lifts for Vince also, because that was about his only male companionship. So, fitting the patient to the caregiver is extremely important." Due to the close contact that occurs during this very difficult illness, the professional home health aide can practically become a member of the family during the latter stages of the disease.

The RN checks in with ALSA-FL if additional resources are needed for the patient, such as assistive communication devices, TDD machines that enable patients to make phone calls, or wheelchairs such as the one Vincent received. In this way, RNs act as an extension of ALSA-FL staff, providing the ALS patient with a continuum of care that consists of professional dialogue and feedback.

When more specialized problem solving is required, this continuum is critical to the ALS patient. "One woman in particular has no family support—her husband and her children won't take care of her," says RN Alice Nichols. "She's alone all day and she didn't have a way of eating unless they'd give it to her and they would withhold food. Christine [Bright of ALSA-FL] and myself were able to get some things in the community going for her. Some Meals on Wheels in her area, then, tied in with her church, a woman who is committed to assisting her, and being her advocate during the day when she is alone. And it has so much impact on this woman in particular."

The patient or family decides how to use the respite care funds. Some choose to use the funds to hire an aide for a weekend, so that they can have some worry-free, quality time to themselves. Most caregivers use an aide for an hour of care for three to five weekdays each week. This way, patients' loved ones are assisted with physical and time-consuming morning tasks, so that the caregiver either has extra help, time to prepare for work or time to send children off to school.

"We would have a home health aide who would come in, and get my husband up, and brush his teeth, let him go the bathroom, shower him and then get him in his chair for the day," says Diane Miller. "It was very difficult for me to get up in the morning—and I have three kids, get them off to school on time—and for me to do all of that, too.... I was at the point of exhaustion as it was. It was a lifesaver. I don't know what I would've done without the help that ALSA gave us during the first couple of years."

ALSA-FL's respite program relieves family caregivers by funding aides who assist ALS patients and families with the following activities of daily living:

- Lifting the patient from a bed to a wheelchair or to the bathroom
- Assisting the patient with bathing, showering or using the toilet;
- Brushing teeth, dressing the patient and otherwise helping the patient start the day;
- Feeding the patient or administering nutrition through a feeding tube;
- Suctioning excessive saliva;



- Operating nebulizers, non-invasive ventilators and other medical equipment; and
- Carrying out chest therapy and range of motion exercises.

The respite care is a relief to patients, as well, who worry about the strain on their families. ALS patient Cynthia Blacker calls it “a godsend.” She relied heavily on the respite care for a time after her primary caregiver, her husband, died unexpectedly. “Having people here, it changed my whole attitude. I was very lonely after my husband died. They *literally* saved my life...I was definitely suicidal.” Now her son is helping her, and he is benefiting from respite. “The fact that I’ve been a slow progressor...,” Ms. Blacker explains, “I think of my poor son, having to do this for the past two years, and who knows how much longer...I want to give Michael as much time as he can get *away* from it. Try to think of something else without worrying about me, and when I have the respite care he doesn’t *worry*. You know, I’ve got nursing care here, there’s no reason to worry. It’s *wonderful*.”

If there ever is a problem with a home health aide, the family is instructed to call the agency first. If the problem is not resolved by the agency, the family contacts the ALSA-FL coordinator, who intervenes in order to find a solution or a new agency. After a three to four month period, the ALSA-FL coordinator helps determine if respite care should be extended or if the patient should transition to other services such as hospice.

#### *Training for Home Health Professionals*

The ALSA-FL *Chapter RN* will conduct an in-service program for home health professionals once a month. These programs, presented successfully to 20 professionals in 2002, deal with a variety of issues unique to ALS patients. They help ensure that the home health professionals are comfortable and fully competent when working with ALS patients.

Because many more Florida home health professionals require training, ALSA-FL will increase its RN’s training hours in 2004 to provide instruction to 120 home health professionals. Classroom space for the trainings is provided by participating agencies. ALSA-FL provides the educational materials and the trainer, and works with the host agency to market the training to home health professionals. A Durable Medical Equipment (DME) company provides equipment used for demonstration purposes during the training.

Training topics include:

- ALS basics, such as what it is, who gets it, types of ALS types and survival statistics;
- Diagnosis of ALS, ALS resources and theories regarding the cause of the disease;
- ALS symptoms, stages and special health/safety concerns associated with the disease;
- Management and treatment/clinical pathways addressing ALS;
- Pharmaceutical, non-pharmaceutical and multidisciplinary approaches to ALS;
- Assistance with decisions regarding matters such as Living Wills; and
- Information on ALS clinical trials, patients’ rights and strategies for addressing ALS.

Educational materials distributed to training participants include *Living with ALS* manuals, details about ALSA-FL programs and a list of multidisciplinary clinics in Florida. Each training lasts from 4 to 6 hours, depending on the needs of the training participants.

## **Project Staffing**

**Dara Alexander**, *Executive Director* of ALSA-FL, will oversee the proposed project. Ms. Alexander has 24 years of experience in program management and became involved with ALSA as a volunteer when her father contracted the disease. She is a member of the national ALSA Board of Trustees and is a Past President of both ALSA-FL and ALSA's Western Ohio Chapter. Prior to directing of ALSA-FL, Ms. Alexander was recognized by the national ALS Association as Volunteer of the Year.

**Christine Bright, MSW**, is the *Respite Care Program Director*. Ms. Bright holds a Bachelors degree in Education from Indiana University and a Masters in Social Work from Florida State University. She interned in a multidisciplinary setting at the Veterans Administration and has several years of experience with state agencies including the Agency for Health Care Administration and Medicaid. Ms. Bright is a full-time employee based in Tampa who spends an average of one day a week coordinating respite care services, such as administering the program, and meeting with caregivers, patients and families involved with respite. She directs the statewide Respite Care Program and coordinates patient services in Hernando, Pasco, Polk, Pinellas and Hillsborough Counties.

**Barbara Grasmann, LMFT**, serves as full-time *Patient Services Coordinator* for Palm Beach, Broward and Dade Counties.

**Susan Weber** serves as part-time *Patient Services Coordinator* for Manatee, Sarasota, Charlotte, Lee, Collier, Hendry, Glades, Desoto, Hardee and Highlands Counties.

The ALSA-FL *Chapter RN* conducts the monthly in-service program for home health professionals. **Andrea Bozeman, RN, BSN**, recently resigned from this position and a replacement is now being sought.

**Robin See** is a *Respite Assistant* who works part-time for ALS. Ms. See assists with program billing, typing, mailings and other administrative duties.

**Bruce and Dottie Burkett** are volunteers who serve as locally-based contacts for ALSA-FL respite care participants in Southeast Florida. They also provide other services for ALSA-FL, such as management of an equipment loan closet for that region.

## **Collaborators**

ALSA-FL collaborates with several other nonprofit, public and private organizations that provide services to ALS patients and their families.

ALSA-FL participates in the Florida Respite Coalition (part of the National Respite Care Coalition), which envisions a coordinated, supportive and fully funded system of lifespan respite care in Florida. The Area Agencies on Aging throughout Florida are ALSA-FL collaborators that sometimes provide day care for elderly ALS patients.

ALSA-FL works closely with reputable private agencies that provide professional home care, such as Bayada Nurses, Catalano's Nurses, Housecalls, Gentiva, Kelly and Health Matters. Hospices, such as Hospice of Palm Beach and Hospice of the Florida Suncoast, are additional ALSA-FL partners. Other organizations that partner with ALS include Broward Homebound, Meals on Wheels, American Red Cross and various transportation providers.

ALSA-FL contracts with two nonprofit organizations to house, maintain and loan donated assistive communication devices to ALS patients who cannot speak due to paralysis. These organizations are the Florida Alliance for Assistive Services & Technology, Inc. (FAAST, Inc.) West Central Regional Center and Nova Southeastern University (NSU) in Fort Lauderdale. ALSA-FL also funds training on these devices through NSU and FAAST, Inc. Both organizations conduct communication evaluations for ALSA-FL patients with Medicare or private insurance coverage.

ALSA-FL collaborates with Shells Seafood Restaurants, Inc., which has 28 locations in Florida, to educate the public about ALS. This connection was made through Tina Rodriguez, an ALSA-FL client and Shells employee who was diagnosed with a hereditary form of ALS. In August 2003, Shells will begin selling "baseball mobiles" at all of their locations. For every \$2 mobile purchased, \$1 will go toward ALS research and \$1 will be earmarked for local patient services programs. Representatives from ALSA will attend two statewide manager meetings to educate Shells employees about ALS and wait staff in all 28 restaurants will wear baseball-shaped stickers with the phrase "Ask Me About Tina." Tina will visit Shells restaurants to talk to employees about what ALS means for her future and this fall brochures for the chapter's *Walks to D'feet ALS* will be available at Shells locations.

Because the most famous ALS patient was baseball great Lou Gehrig, ALSA-FL enjoys many healthy collaborations with athletic teams. In addition to its Dine with the Devil Rays fundraisers, ALSA-FL is featured on announcement boards and Jumbotron at Florida Marlins and Tampa Devil Rays Major League Baseball (MLB) games. Minor League baseball teams in Florida commemorated Lou Gehrig's 100<sup>th</sup> birthday on June 19, 2003 by helping to publicize ALS and ALSA-FL. That day, the first 25,000 people to arrive at ballparks received special Lou Gehrig baseball cards featuring facts about the player, as well as ALS facts and ALSA-FL contact information.

ALSA-FL has agreements with five Durable Medical Equipment (DME) companies. These companies house, maintain, pick up and deliver donated equipment such as shower chairs and wheelchairs to ALS patients at no charge. DME companies also help ALS patients determine which equipment is covered by their insurance providers.

ALSA-FL support groups receive in-kind gifts of space from many collaborators, including Shands Medical Center, Sarasota Medical Center, Cypress Lake United Methodist Church, Northwest Medical Center, Holmes Regional Medical Center, Arbor Oaks, Collier County Library, Center for Independent Living, Pasco County, Paddock Park South Community Clubhouse, Morton Plant Mease Outpatient Center, Martin Memorial, Tampa General Rehabilitation Center, Ormond in the Pines, Cleveland Clinic and Winter Haven Hospital.

## **Evaluation**

ALSA-FL measures the effectiveness of its education efforts for ALS patients and their caregivers through surveys. An identical survey is given both before and after education efforts are completed by an ALSA-FL patient services professional. The Respite Care Program Director will also keep records of skills or concepts that are taught to caregivers.

The amount of respite care funds and hours of respite care provided will be tracked by the Respite Care Program Director. Documentation for these services will include accounting records and agreements between ALSA-FL and ALS patients or caregivers.

The Respite Care Program Director will similarly track the number of trainings provided to home health professionals who lack experience with ALS patients. Sign-in sheets from the trainings will be used as documentation. In addition, the professionals attending the trainings will complete evaluation forms to measure what they have learned and to collect feedback regarding future ALS trainings and topics.

ALSA-FL will track referral sources as part of its intake process to determine if more medical professionals and members of the public are referring ALS patients. The Respite Assistant will compile this referral information, and keep track of marketing conducted through the project, to ensure that objectives are met.

**Thank you for reviewing our information. We appreciate any support you are able to provide toward our mission to cure ALS and enhance the lives of those who suffer from it.**