

## **Summary of 2016 program accomplishments**

The Joe Martin ALS Foundation's mission is to help people with ALS (PALS) live actively. During the period of January 2016, through December 2016, the Joe Martin ALS Foundation provided 61 families face the challenge of living actively by providing assistance with home care services. The Carolinas Neuromuscular/ ALS Clinic and ALSA Catfish Hunter Chapter refers these PALS to the foundation. For the families we help 2 times per week (35 in 2016), we provide assistance with getting out of bed and preparing for the day, perform ADL's (activities of daily living, such as bathing, dressing, toileting, hygiene tasks, etc.) exercise therapy, range of motion, wheelchair accessible transportation, travel planning, and assistive computer loans and tech support. These visits average 2.5 hours per visit.

We work with the ALS clinic staff to tailor individual range of motion and exercise programs, loan homecare equipment, and facilitate communication from patient to clinic staff to meet our PALS' needs. Our "client update" program provides the ALS clinic staff with monthly updates about changes our PALS are experiencing and what is needed to help them adapt to new disabilities.

The 26 other families we help received assistance with wheelchair accessible transportation to doctor appointments, to the ALS Clinic in Charlotte, NC, and other outings. We also helped families with travel plans. Calls to hotels, airlines, restaurants, and van rental companies have been made to facilitate wheelchair accessible travel. Additionally, we made arrangements for "beach" wheelchairs so people with ALS can enjoy a beach vacation with their family.

We also provided Caregiver Workshops. These workshops were offered to help families learn the best techniques to care for their loved ones. Participants learned how to safely transfer someone from wheelchair to bed by using a hooyer lift, how to perform range of motion, and use medical equipment that improves ALS quality of life.

In addition, we provided assistance by emailing and talking with caregivers on the phone and by managing and updating HomeLifeforPALS.org. This website serves as a resource for caregivers that includes instructional videos. Our staff has

over 20 years of experience helping people with ALS and we share what we have learned to help PALS face the many challenges of ALS.

Another service we provide is home accessibility assessments. We visited PALS' homes to make suggestions on how their home can be more wheelchair friendly and safer for those who are still walking. We also trained caregivers how to use hooyer lifts, how to safely transfer PALS, and educated PALS' family and friends about caregiving.

### **Assessment and Recommendations:**

An anonymous questionnaire was given to our PALS to assess the Joe Martin ALS Foundation's services. The questionnaire asked our clients what services they received, how pleased they were with the services, the value and importance of these, if the services helped our clients save money, and how the foundation and its services could be improved.

100% of respondents reported they were "Very Pleased" (highest rating) with the services provided by the Foundation.

The value of our services received the highest rating of "Very Important" for 88% of our clients and 12% reported a value of "Important," the second highest rating. 0% of our clients rated our services as "Helpful" or "Unnecessary."

All of our clients (100%) reported our services helped them save money on the cost of homecare and other medical expenses. Only 18% believed any improvements could be made and this involved requests for services the foundation does not offer or provide. Our services are stated in our brochure, on our website, and all clients are informed of our services on initial visits. Our staff members discussed the services provided with our clients after we received the completed questionnaires to clarify what we provide and answer any questions. (The above data is from the 2015 questionnaire survey)

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**Financial Report ( From 2015, update for 2016 will be added after 990 is completed):**

**Income**

210,643

**Expenses:**

| Program        | G & A         | Fundraising   | Total(Budget) |
|----------------|---------------|---------------|---------------|
| 166,349(74.4%) | 25,565(11.4%) | 31,840(14.2%) | 223,754       |

**Ending Net Assests**

221,338