

## Compassionate Care ALS Annual Report 2010

### **The Mission:**

The mission of Compassionate Care ALS (CCALS) is to model compassion to those affected by Amyotrophic Lateral Sclerosis (ALS, also known as Lou Gehrig's disease) by providing educational and legal resources, respite opportunities, instruction and guidance, subsidy of living aids and assistance, and intimate dialogue with patients and their caregivers, families, and friends. Our approach draws from hands-on experience as we strive to continually understand the overwhelming dynamics ALS families endure.

### **The Need:**

ALS is a degenerative and fatal disease that progresses unpredictably. The challenge of caring for an ALS patient puts an enormous strain on friends and family – emotionally, psychologically, spiritually, and financially. ALS can strike without warning: anyone- regardless of race, gender, income, education, or geography can be affected.

### **The CCALS Difference:**

Compassionate Care ALS maintains a holistic presence with ALS patients their families and ALS caregivers. We strive to accompany them on their journey, actively listen to their concerns, providing care for their needs, and equipping them to face end of life issues with dignity and grace. Thanks to the support of individual donors and foundations, CCALS is growing, and in 2010 we were able to help 340 families. More than we ever have in a single year and a 15% increase from 2009.

### **ALS Patient, Family & Caregiver Support Program:**

When a family receives the devastating diagnosis of ALS, they are faced with an overwhelming array of questions, paperwork, medical advice, financial and logistical challenges, and life-altering changes. Conventional medicine does not begin to address the complexity of these needs. That is where CCALS steps in to fill the void in services. Our *ALS Patient, Family, and Caregiver Support Program* includes making home visits to meet with families face to face; engaging in intimate dialogue around disease progression, dying and death; helping families obtain durable goods not covered by insurance; and referrals to numerous specialists. In addition, we loan our wheelchair-accessible van to families for everyday needs and special trips.

### **Cultivating Compassion:**

Our hands-on experience with ALS families has given us wisdom and perspective we are eager to share with others. That is why we created the *Cultivating Compassion* education series, which informs individuals living with ALS, families, friends and healthcare providers about the realities of living and dying with ALS. The series consists of several different workshops on an array of topics related to ALS care. Attendees might learn about Living with ALS, Providing Compassionate Care, Awakening to Living and Dying, Care of the Caregiver, or Meditation and Contemplative Practice. CCALS also holds groups for specific populations like Men of ALS, Women of ALS, Beyond ALS (for those who have lost a loved one to the disease) and in-services for hospice organization staff. CCALS hosts many of these gatherings, while some are hosted and organized by health care agencies who want to educate their employees with the benefit of our expertise. During 2010, CCALS provided 21 workshops to more than 410 individuals.

**Van Program:**

The van program is an integral part of CCALS that gives families back their mobility. Families use the van for everything from weekends away with loved ones, to grocery shopping and trips to the movies, everyday experiences often taken for granted until the ability to have them is gone. For some individuals, this is the only alternative to costly ambulance trips for leaving the house. Our van was used by 22 different families during 2009.

**ALS Medicine Bag:**

Over the years, one of the ways that we have supported ALS families is by providing them with equipment on an as-needed basis to help ease daily life around the house. CCALS has used our 12 years of experience working with ALS families to put together a collection of the best non-institutional resources that help bring dignity to those living with ALS. We have now compiled these resources into our new Medicine Bag, which we give to all new patients and families. It contains products like Transfer Belts and Transfer Slings, that help patients stand and transfer from one space to another, and Pivot Disks, on which the patient stands to move from one location to the next when they can no longer move their legs. The Medicine Bag holds items families might not anticipate needing when first diagnosed, but will be grateful to have at their disposal down the road.

**The Future:**

For people living with ALS, the future can be filled with fear, uncertainty, and dread. At CCALS we are working to transform that reality into one of peace, mindfulness and compassion. As we look ahead we hope to continue to expand our array of services and educational opportunities, to better equip families and patients living with ALS to face the future with hope and dignity.

**Funding:**

This year CCALS raised more than \$720,000 to support our programming including contributions from 3,618 individuals who donated over 610,000 and accounted for 85% of our funding. We received grants from 6 foundations. We are constantly working to diversify and increase our base of support, because we know every dollar raised somehow touches a family devastated by ALS.

**What your generosity accomplished in 2010:**

- Helped us increase the amount we raised in the Falmouth Road Race to more than \$244,000, again making us the second leading fundraising charity at the race.
- Provided services to 310 ALS families including 134 new cases.
- Made possible 490 visits to people living with ALS and their families at home to provide guidance and emotional support, to assess their current circumstance and to deliver equipment.
- Conducted more than 1,000 phone consultations with ALS patients, families and friends.
- Meetings with caregivers one on one to listen and offer support.
- Arranged hands-on integrative therapy sessions from trained physical therapists, counselors and other healthcare professionals.
- Provided families with ramps, wheelchairs, shower chairs, lifts, and other durable goods not covered by insurance or provided by other organizations.