



**Ray Carson, Southeast Territory Executive**

# The ALS Association

## Covering All the Bases

**Research**

**Advocacy/Public Policy**

**Care Services**

**Fundraising – Sustainability –Volunteering**

# The ALS Association

## Fund Global Research

- The largest private funder of ALS research worldwide.
- Thanks to the ALS Ice Bucket Challenge, we are now spending three times more than on ALS Research than before summer 2014.
- Supports a wide breadth of specific fields of study that are critical to advancing ALS research (AT, Biomarkers, Disease Models/Mechanisms, Clinical Studies, Genetics, Drug Development, Stem Cells etc.)

# The ALS Association

## Public Policy

The ALS Association is aggressively advocating for legislative priorities that will help to:

- Find New Treatments and Cures
- Optimize Current Treatments and Care
- Prevent or Delay the Harms of ALS

# The ALS Association

## Public Policy

### Federal Accomplishments

- **National ALS Registry** (launched October 2010)
  - Single largest ALS research project ever created.
  - Designed to identify ALS cases throughout the United States via an online web portal, as well as from existing national health databases (Medicare & VA)
  - Collecting critical information about ALS that will improve care, help us learn what causes ALS, how it can be treated and even prevented.
- **Veterans Benefits**
  - Established ALS as a 100% service-connected disease (Sept 2008)
  - Vets with ALS and survivors have over \$500M in benefits - disability compensation and full health care.
- **Waiver of waiting periods for Medicare (24 month) and SSDI (5 months)**
- **FDA Advocacy – Relyvrio (2022) and Toferson (2023)**

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## Public Policy

### State Accomplishments

- **Bitner Plante ALS Initiative of Florida**
  - Established July 1, 2013
  - Provides state funding to support Florida's Certified Centers of Excellence
  - Results:
    - 6-7 clinic days per month in 2013 vs. 22.5 clinic days per month today

# The ALS Association

## Programs & Services

- Specialized Care Consultation
- Education and Outreach
- ALS Resource Support Groups (currently virtual)
- Equipment Loan Program
  - Durable Medical Equipment
  - Communication Devices & Assistive Technology
- Financial Assistance Programs
  - Care Assist grants
  - Scholarships
  - Transportation grants
- Multidisciplinary Clinic Partnerships

# Program Partners: Clinics

## **Certified Centers of Excellence**

- Mayo Clinic – Jacksonville (6-7 per month)
- University of Florida – Jacksonville (4 per month)
- University of South Florida – Tampa (4 per month)
- University of Miami – Miami (8 per month)
- Holy Cross Health – Ft. Lauderdale (5 per month)

## **Affiliated Clinics**

- University of Florida – Gainesville (2 per month)
- Orlando Health - Orlando (2 per month)
- Advent Health - Orlando (1 per month)
- Lee Health – Ft. Myers (4 per month)
- Sarasota Memorial – Sarasota (1 per month)
- NSU Health – Davie (4 per month)
- West Palm Beach VA – (1 per month)



# How we do it ...

## **Volunteer Opportunities**

- Public Policy Advocates
- Event support

## **Rally Communities**

- Walks to Defeat ALS – 9 in Florida
- CEO Soak – 5 in Florida
- Ride to Defeat ALS – Kissimmee, FL
- Ring of Honor Golf Tournament – St. Augustine, FL