LES
TURNER
ALS
FOUNDATION™

Les Turner ALS Foundation

Founded 1977

Wendy Abrams

December, 2014

Who Was Les Turner?

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Les Turner

- Les Turner, a Chicago area businessman, husband, and father, was diagnosed with ALS in 1976.
- Frustrated by the lack of information and research on ALS at the time, he and his family and friends started the Foundation in 1977, just a year before Les' death at age 38.

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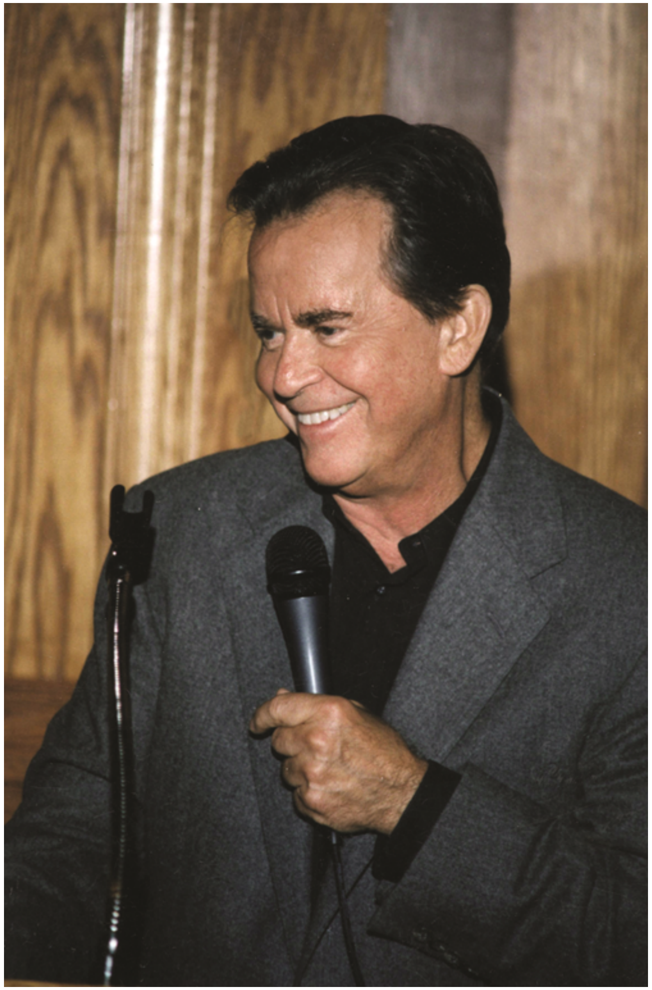

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Mammoth Music Mart with Dick Clark

Teepu Siddique, MD
Since 1991

Hande P. Ozdinler, PhD.
Since 2008

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Les Turner ALS Foundation Research and Patient Center at Northwestern Medicine named in October, 2014.

Burk Jubelt, MD
Shari Diamond, RN, BSN
Scott Heller, MD

Pat Casey, MS, OTR/L, CCRC
Jennifer Armstrong, RN, MSN, MHA

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The Lois Insolia ALS Clinic at Northwestern Medicine since 1986, is the Patient Center.

After the Diagnosis…What Then?

Be Proactive

Contact ALS Experts

Maintain Nutrition and Hydration

Maintain Hope

Begin Rilutek

Maintain Breathing Health

Stay Active

Les Turner ALS Foundation ALS Patient and Family Support Programs

- These free programs are available to ALS patients and their caregivers who reside in the Foundation's service area, and offer a continuity of care from physician to the home and community.
- Home and Community Services Team
  - The Team: Consists of 6 Patient Advocates, 4 Nurses and 2 Social Workers

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Home and Community Services Team

- Enhance the continuity of care between Center Visits
- Provide ongoing disease education and address specific concerns
- Provide practical information on quality of life and daily living
- Provide home environment safety assessment, adaptions and equipment
- Facilitate communication between patient, family members and the healthcare team
- Share information regarding disability, Medicare, Medicaid, private insurance and other financial options
- Guide access to care through state programs, caregiver services and explore additional means to maximize assistance
- Assist with advance directives; including living wills, medical power of attorney and other end of life issues
- Provide social service support and intervention to improve communication and assist in conflict resolution
- Consult with home health agencies and hospices to coordinate care
- Conduct in-service education for home health agencies, hospices, case management groups, assisted living facilities, nursing homes, a patient’s employer and other community organizations
- Provide bereavement Support

Additional Program Services

- Telephone, e-mail, skype and referral support
- Support group meetings for patients, families and caregivers
- Durable medical equipment loan banks
- Communication equipment
- Ralph Russo Patient and Family Services Grant Program
- Dan Nelson ALS Respite Grant Program
- Stuart Rosen ALS Transportation Program
- Educational materials and programs

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Home and Community Services Team & PALS

Focus of Home Visit

- Coping
- ADL
- Mobility
- Speaking
- Swallowing
- Breathing
- End-of-life care

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Coping with ALS

- Stages of coping
  - ALS is a disease of continuous change and loss
  - Change in roles, independence, living arrangements, privacy

- Knowledge is power
  - Support groups empower patients by:
    - minimizing isolation and promoting open exchange of education on various aspects of the disease
    - Working with ALS experts and ALS specific groups

- Understanding and treating emotional lability and depression
  - Use of anti depressants, counseling
  - Medications for emotional lability

- Facilitating sleep and comfort
  - Assess for muscle cramping, muscle aches due to contractures, fear and isolation

Activities of Daily Living

- Hand and arm weakness
  - Associated problems include:
    - eating, dressing, bathing, grooming, toileting

- Assess level of independence, identify ways to maximize self care

- Occupational Therapy evaluation
  - Equipment needs
  - Home Safety evaluation
  - Adaptive devices and other tools

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Mobility

- Leg and upper limb weakness
  - Associated problems include:
    - Foot drop, tripping, instability, difficulty rising from seated position, cramping, decreased endurance

- Physical Therapy evaluation
  - Assessment of muscle strength, gait, endurance, balance
  - Assessment walking, transfers, positioning
  - Equipment evaluation
    - AFOs, walkers, canes, wheelchairs

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Mobility

- Energy conservation and compensatory techniques
  - Planned rest periods during the day
  - Alternating b/t heavy and light tasks
  - Setting priorities and eliminating unnecessary tasks
  - Sitting instead of standing when able
  - Make work area handicap accessible

- Manage stiffness, cramping and pain

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Speaking

- Evaluation by speech and language pathologist (assess dysarthria, tongue, lip and jaw weakness, involvement of vocal cords and respiratory muscles)

- Use compensatory techniques (e.g. slow down speech, concise phrasing, exaggerated articulation)

- Simple communication tools (magic slates, letter boards)

- Augmentative communication devices (sensor or switch activated computers, IPad 2)

Swallowing

- Nutritional evaluation
  - Monitor weight, observe for difficulty chewing, weakened jaw or lip muscles, time needed to eat meals, assess hydration and nutritional status
  - Nutritional supplements

- Swallowing evaluation by SLP

- Swallowing and dietary modifications
  - (e.g. head position- tuck chin down during swallow and repeat swallow as needed to clear residue avoid food with difficult textures, minimize thin liquids

- Assess consistency of secretions, ability to manage saliva
  - Monitor for gagging and choking
  - Use of portable suction, hydration, medications to thin secretions, avoid dairy products

- Alternative feeding device
  - PEG tube

Breathing

- Pulmonary evaluation and testing (FVC q 2-3 mos)
- Vaccine for flu or pneumovac
- Energy conservation, breathing exercises
- Chest PT, assistive cough techniques (adequate H2O, avoidance of dairy products and chest PT to < thick phlegm) OTC and prescription meds to assist secretions, use of nebulizer and suction
- Invasive and non invasive breathing devices (50% of predicted FVC is an indicator it is time to initiate respiratory assistance)
- Discussion of respiratory care options and advanced directives before respiratory crisis occurs

Respiratory Function in ALS

- Neuromuscular diseases cause interruption in normal airway clearance
- Chest infections a serious threat in ALS
- 90% due to upper respiratory tract infections
- Pneumonia is common source of morbidity and mortality
- Respiratory failure is most common cause of death in ALS

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Airway Clearance Protocols

- Rhinitis control
- Salivary control
- Nebulizer – to moisten or dry secretions
- Vest - mobilizes secretions
- Cough Assist and Suction machine – evacuate secretions
- NIV (Bipap, VPAP, IVAP, Trilogy)
- Breathing stacking exercises – prevents atelectasis, ROM for chest wall, clears nose/throat

Diaphragm Pacer System

- FDA approved under Humanitarian Device Exemption program
- Improves respiratory function
- Surgically implanted via laparoscopy
- Electrodes stimulate diaphragm to contract
- Patient controlled; usual use at night
- synapsebiomedical.com

Sleep and Comfort

- Assess for sleep disturbances caused by:
  - stiffness, cramping, depression, nocturia, isolation and fear, compromised breathing status and generalized discomfort due to inability to change position

- Comfort Measures to try:
  - Stretching exercises may decrease muscle cramping and stiffness
  - HOB elevated can ease breathing difficulties
  - Repositioning patient off of bony areas use of pillows and wedges, sheep skin and air or gel mattresses
  - Reassure patient that you will check in frequently
  - Medications for symptomatic control

End-of-Life Care

- Facilitate family, patient and care giver communication early in the course of the disease and maintain on going, open and honest discussions
    - Patient and family counseling on disease progression, advanced directives (the patient's wishes pertaining to feeding tube, invasive and non invasive ventilation, autopsy and tissue donation)
- Patient and family support, education
    - Les Turner ALS Foundation
- Referral to hospice
- Dignity and Comfort
- Symptom management

Complementary and Alternative Medicine

- Acupuncture
- Massage Therapy
- Holistic
- Meditation

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Getting Involved in Research

- Clinical trials
- National ALS Registry
  - Program to collect, manage and analyze data about people with ALS that is critically needed for ALS research, disease management and the development of standards of care
  - www.cdc.gov/als
- Tissue donation and autopsy

Les Turner ALS Foundation Fundraising Events

- ALS Walk for Life
  - Arts4ALS
- Run for ALS
  - Strike Out ALS 5k
  - Iron Horse 5k
  - Chicago Marathon
  - Shamrock Shuffle
  - Fitness in Motion 8k
- Swim for ALS
- Hope Through Caring Award Dinner
- ALS Awareness Month Tag Days
- Third Party Events
- YPG, Young ProfessionALS Group

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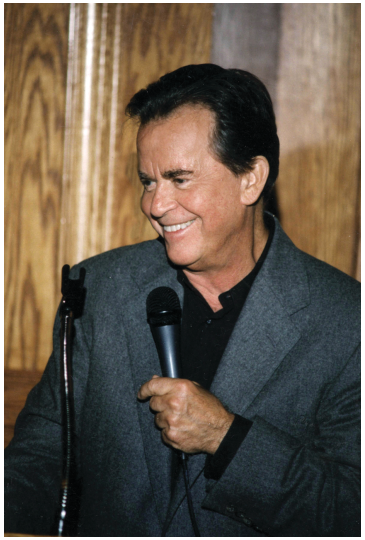

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Spokespeople and Media

International Alliance of ALS/MND Associations

- Founding member, 1992
- Hosted in 1996 and 2012
- Served as a board member for many years
- Chair from 1999-2001 and Interim Chair in 2013