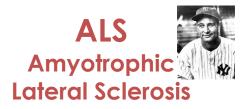
"Never, Ever Give Up"



### Improving Access to Support Services and Care Strategies from Health Agencies Focused on ALS

Leo Rafail, BSW Care Services Program Manager The ALS Association Indiana Chapter

August 15, 2014 1:30 -2:30



Lou Gehrig's Disease



What people see as Lou Gehrig's Disease









July 4, 1939

43





### What does a neurological disease look like?



### A closer look at ALS

- Amyotrophic Lateral Sclerosis (ALS), or Lou Gehrig's Disease
- A progressive, degenerative, neurological condition of unknown origin
- Affects people of both sexes, all races, and all walks of life; Adult risk is 1:500
- · People diagnosed with ALS have their lives cut dramatically short
  - On average a life expectancy of only two to five years
    Only half live past three years after diagnosis
  - · Only one out of ten patients will live for more than ten years
- In 2013, 80 people with ALS in ALSAIN database died
- In 2013, 90 people in the ALSAIN database were diagnosed with ALS
- At any given time, there are about 350 people in the ALSAIN database with ALS
- The average age for a person who is first diagnosed with ALS is 55
- · Military Veterans are twice as likely to get ALS
- Often misdiagnosed
- The progression of the disease for most patients is very fast; not a steady decline •
- Each person with ALS has a different presentation of symptoms
  The outcome is always the same: premature death
- As the disease progresses:
- The person is robbed of life-sustaining functions
   Eating

  - Drinking
  - SwallowingBreathing
- All while the person remains:
  - Cognitively intact
     Alert
  - Feeling
  - They are still the same person
- Their strength diminishes:
  - · Their breathing becomes increasingly more labored and shallow

  - Their speech fades
    They can no longer swallow safely
  - · They require increasingly more care.

## How can you help people who are affected by ALS...



### Indiana Chapter

Create a world without ALS.

### Approaches for progressive Neurological Diseases

"I am not dying but I am living with a disease that can utilize technology which will perhaps indefinitely prolong my life. I am still a useful being and will do everything to stay alive." "I know what quality of life means for me. For the time I feel I have an acceptable quality of life, I choose to live with this disease.

That said, I have chosen not to utilize certain interventions to prolong this disease. "

### Critical Periods for Patient and Family Stress

- Receiving a diagnosis
- · Early signs of disability
- Need for occupational changes
- Losing ability to drive safely
- · Feeding tube, breathing assistance (ALS)
- Emergence of severe health problems
- Considering home health
- · When out-of-home placement is being considered
- · Considering palliative care and hospice

ALS Association Certified Center of Excellence

# HEALTH

### Indiana University ALS Clinic uroscience Building 3oodman Hall 16th Street, 3rd Floor an apolis, IN 46202 355 W out your visit

•	Please Be Patient! The team assists pu bents who are experiencing complex issues Because the clinic strives to provide the besi care to everyone, expect that your visit will last at least 4 hours		
•	Please bring any medications you are curre taking		

ave a trusted adult The clinic is an ex obtain medical services from a specialized beam, and is, therefore, a great place for med-cal students and medical residents to learn about ALS. At your visit there will protobly be some students and residents along with the care team.

### ndiana University ALS Clini Office (317) 963-7385 amicheel@upui.edu Parter (317) 313, 2389

nic FAX: (317) 963-7533

ager (317) 312-2288	
kuingilch, LPN, CCRC ffice (317) 963-7382 guingri@iupui.edu rager (317) 312-1539	

Pł	vsical Medicine and Rehabilitation Team
·	*Dr. Prahlew," Nathan Prahlew, MD Physical Medicine and Rebab Physician
:	"Patti, Patti Witczak, PT "Christen," Christen Kring, PT Physical Therapists
•	"Ryan," Ryan Neyenhaus, OT Occupational Therapist
•	"Peter," Peter A, Coek, CO Certified Othotist
:	"Ed," Ed Thom, ATP "Terry," Terry King Medical Equipment Specialists
Re	spiratory Therapy;
•	"Brendia," Brendia May, RT Respiratory Therapist
Sp	eech and Nutrition Team:
•	"Rachelle," Rachelle Bates, MS, CCC-SLP Speech Therapist
•	"Saily," Saily Guerra, RD Registered Dietition
<u>C</u>	re Services and Social Work Team:
:	"Heather," Heather Hudson, MSW "Leo," Leo Rafail, BSW The ALS Association Indiana Chapter
ci	nic Coordinators:

Who's Who in the ALS Clinic:

"Dr. Pascuzzi," Robert Pascuzzi, MD ALS Specialist Neurologist
 "Dr. Bodbin," Cynthia Bidkin, MD ALS Specialist Neurologist Sleep Medicine Specialist

Neurology Team:

"Sandy, " Sandy Guingrich, LPN, CCRC "Angi," Angi Micheels, PT



- ALS is a presumptive condition for VA Service Connected Disability benefits
   All Veterans who develop ALS at any time after separation from service may be
  - eligible for compensation for that disability The VA offers many benefits that are essential in caring for a patient diagnosed
  - with ALS • medical care and services including a multidisciplinary ALS Team, adaptive
  - equipment, medications, home health care, nursing home benefits, and home modification
- The Indianapolis VA is the appointed site for the VISN 11 Region
  - Offers a multidisciplinary approach to ALS care
  - Provides intensive case management services to Veterans who have been diagnosed with ALS and their families





### l am a caregiver for someone.

If I am incapacitated, please immediately notify:

My loved one is dependent upon me and requires assistance.



Thank You.

### Living With ALS Videos

- Mobility, Activities of Daily Living, Home Adaptations
- Adjusting to Swallowing Difficulties and Maintaining Good Nutrition
- Communication Solutions and Symptom Management
- Clinical Care Management
- Adapting to Breathing Changes and Use of Noninvasive Ventilation

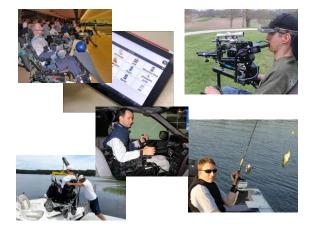




- Benefits
- Caregivers TopicsNewly Diagnosed
- For People with ALS
- Research / Clinics
- Speech / Swallowing







Thank you for your interest in learning about ALS and The ALS Association Indiana Chapter.

You will have many opportunities to improve the lives of people with ALS and their friends and families.

### CARE GIVER PRAYER

As I stumble through this life, help me to create more laughter than tears, dispense more happiness than gloom, spread more cheer than despair. Never let me become so indifferent that I will fail to see the wonder in the eyes of a child or the twinkle in the eyes of the aged. Never let me forget that my total effort is to cheer people, make them happy and forget at least for a moment all unpleasant things in their lives.

And, in my final moment, may I hear you whisper:

"When you made My people smile, you made Me smile."

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