

Les Turner ALS Foundation

# **RESOURCE GUIDE**

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# INTRODUCTION

## The Les Turner Story

Les Turner was a successful Chicago-area businessman with every prospect of a bright future. In 1976, at age 36, he was diagnosed with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. Though he knew he only had a few years to live, Les dreamed of the future: to someday find a cure for ALS. Despite his increasing paralysis, Les worked toward making that dream come true - not only for himself, but also for all ALS patients, present and future.

Les was 38 years old when he died. In December of 1979, his dream began to materialize: the Les Turner ALS Research Laboratory was dedicated at Northwestern University Medical School.



Les Turner

Les, his family, and his friends established The Les Turner ALS Foundation in 1977. They formed the organization to unite their fundraising efforts for ALS research, while also providing support to Les and his family. Today, the Foundation is one of largest independent, publicly supported organizations in the country devoted to raising funds for ALS research, patient services, and public awareness and education.

The Foundation is affiliated with Northwestern University's Feinberg School of Medicine in Chicago, Illinois. With their encouragement and support, the ALS community is offered the most promising research programs, an excellent professional staff, a comprehensive patient care center and the most current educational programs available.

The Lois Insolia ALS Patient Center opened in September, 1986 at Northwestern Memorial Hospital. It was established through the generosity of the James V. Insolia family, whose loving wife, mother, and grandmother, Lois, will long be remembered for her courage, dignity, and style.

The Center utilizes a multidisciplinary team approach to care for people with ALS. Trained specialists provide diagnostic, rehabilitative, and supportive services

focusing on assessment, care planning, and education. The team members have put their experiences in the resource book to help support patients, family members, and caregivers.

The International Alliance of ALS/MND Associations was inaugurated in 1992, and the Les Turner ALS Foundation was a founding member. The Alliance exists to provide mutual support among associations, offering a forum for information exchange and the development of ideas on good practice.

This is the third edition of our Resource Guide. We are deeply grateful to Aventis Pharmaceuticals for helping underwrite the cost of this edition of the book.

ALS is a difficult disease with which to cope; our focus here is to provide as much information as possible to help people living with ALS while research to find the cause and a cure continues. High through-put drug screening, the development of ALS mouse and rat models, mapping of the human genome, and increasing public awareness of ALS leading to more funding for research, are all helping to speed the process. The first gene responsible for familial (inherited) ALS, SOD1, was identified in 1993. The first FDA-approved medication for the treatment of ALS, Rilutek, became available in 1996. Since that time, two retrospective studies presented at the 12<sup>th</sup> International Symposium on ALS/MND, in Oakland, California in 2001, indicated that Rilutek appears to have a greater impact on life expectancy than was reported in initial drug trials.

Until a cure is found, the Foundation will continue to do all it can to support ALS research and provide clinical and patient care services. To everyone who contributed to the updating of the Resource Guide, I commend you on your dedication to helping us provide such a vehicle to improve the quality of life for everyone living with amyotrophic lateral sclerosis.

Wendy Abrams  
*Executive Director*  
Les Turner ALS Foundation

## STAFF DIRECTORY

Phone numbers of the staff members of the Lois Insolia ALS Center and the Les Turner ALS Foundation and other useful phone numbers are listed.

**PHYSICIANS** can be reached through the Clinical Nurse Coordinator at 312-695-5886. They provide the following:

- A diagnostic work-up for neuromuscular disorders at the initial Center visit. This includes a physical exam, a neurological exam, and prescribing appropriate testing for diagnosis and treatment of symptoms.
- Follow-up appointments for ongoing patient care, in order to help patients manage symptoms.
- Prescriptions for appropriate medications for symptomatic relief.

The Lois Insolia ALS Center physicians are:

**TEEPU SIDDIQUE, M.D.**, Director of the Neuromuscular Disorders Program at Northwestern University's Feinberg School of Medicine since 1991. He is a Professor in the Departments of Neurology and Cell and Molecular Biology and a board-certified neurologist.

**ROBERT SUFIT, M.D.**, a board-certified neurologist who joined the Center in 1992. He is currently an Associate Professor of Neurology and is very active in clinical research trials for ALS.

**SCOTT HELLER, M.D.**, a board-certified neurologist and associate professor in the Department of Neurology and Pediatrics at Northwestern University, who has been with the Center since it opened. He is an attending physician at Northwestern Memorial Hospital.

**CLINICAL NURSE COORDINATOR (CNC):** can be reached at 312-695-5886. The Clinical Nurse Coordinator (CNC) is a registered nurse who performs various functions within the Lois Insolia ALS Center at Northwestern Memorial Hospital. The CNC is the primary contact, or "point person," for the ALS Center. If the CNC cannot assist you with a specific request, she will put you in contact with someone

who can help you. The functions of the CNC include

- Scheduling, rescheduling, or canceling appointments for the ALS Center.
- Arranging and following up on diagnostic tests ordered by the ALS Center physician treating the patient.
- Arranging for referrals or orders for all aspects of home care, including service providers and equipment needs.
- Arranging for consultation with other specialists.
- Communicating with the patient's primary care physician and with other specialists.
- Answering questions related to symptoms, new developments, and treatment options.
- Completing forms for insurance and/or medical equipment needs.

**COMPUTER CONSULTANT:** Steve Wells, ASYST Company, at 847-816-8580

- Assesses a patient's equipment needs.
- Devises individual switching techniques for communication.
- Provides in-home adaptation of equipment and trains patients and families on the operation of augmentative communication equipment.

**DIRECTOR OF PATIENT SERVICES:** Claire Owen, LPN, at 847-679-3311. E-mail [cowen@lesturnerals.org](mailto:cowen@lesturnerals.org).

The Director of Patient Services performs various functions on behalf of the Les Turner ALS Foundation. These include:

- Providing the first contact with ALS patients and family members.
- Disseminating information about ALS and about the Foundation and its services.
- Providing phone support and referrals to other members of the Lois Insolia ALS Center professional staff.
- Acting as the liaison between the Foundation staff and the staff of the Lois Insolia ALS Center.
- Coordinating support group meetings.
- Administrating the loan bank of durable medical and augmentative communication equipment.
- Maintaining referral sources for services such as home health and equipment.
- Coordinating educational meetings, including the Annual General Meeting.

**DRUG STUDY RESEARCH COORDINATOR:** Pat Casey, MS, OTR/L, at 312-695-0774. E-mail [Pcasey@nmff.org](mailto:Pcasey@nmff.org)

- Prepares a list of current ALS drug studies and provides contact phone numbers or websites to patients who are interested.
- Screens prospective study participants for ALS drug studies in which the Lois Insolia ALS Center is participating.
- Conducts study sessions with ALS physicians, attends scientific meetings, and organizes medical records pertaining to study.
- May also provide information on durable medical equipment (DME) and on adaptive aids, in conjunction with the information provided by regular staff occupational therapist.

**GENETIC COUNSELOR:** Lisa Dellefave, MS, CGC, at 312-503-0154. E-mail L-dellefave@northwestern.edu.

Genetic Counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They usually work as part of a team to provide information and support to families dealing with a hereditary or potentially hereditary form of the disease. The functions of the genetic counselor include:

- Taking detailed family histories to assess the contribution of genetics to ALS in a particular family.
- Explaining the various patterns of inheritance for familial ALS.
- Discussing all aspects (medical and emotional) of available diagnostic and predictive genetic testing for ALS.
- Recruiting participants for genetic ALS research studies.
- Answering inquiries regarding the current status of research studies.
- Serving as a resource for family members who may have genetic questions or concerns.

**OCCUPATIONAL THERAPIST:** Margaret McGovern, MS, OTR/L, at 312-926-2526. E-mail mmcgoover@nmh.org.

The Occupational Therapist (OT) at the Lois Insolia ALS Center provides the following interventions:

- Assessing the physical, psychosocial, and occupational needs of the patients through interviews and functional evaluation.
- Providing or introducing treatment as indicated by the assessment. This may include instruction in the use of assistive devices, energy conservation, exercise guidelines, and body mechanics for the caregiver.
- Determining resources for optimal functioning in the home and community. This includes recommendations for home modifications, assistive devices for self care, durable medical equipment (wheelchairs, hospital beds, etc.), and

home or outpatient therapies.

**HOME LIAISON NURSE:** Ileana Mindel, RN, at 312-255-9719. E-mail ileane@mycidco.com

The Home Liaison is a registered nurse who performs various functions for the Les Turner ALS Foundation. These include:

- Providing RN functions at the Lois Insolia ALS Center.
- Maintaining phone support for patients, families, and professionals.
- Making home visits to assess the home environment for any needed adaptations and to facilitate family meetings.
- Consulting with home health agencies and hospices to coordinate care for patients.
- Providing in-services for home health agencies, hospices, case management groups, assisted living facilities and nursing homes.
- Helping families evaluate residential facilities for patients.
- Helping to maintain the inventory of the loaner equipment pool.
- Providing assistance with a living will, medical power of attorney, and end of life issues.

**SPEECH AND LANGUAGE PATHOLOGIST:** Sharon Veis, MA, CCC-SLP, at 312-926-3705. E-mail s-veis@northwestern.edu.

The Speech-Language Pathologist (SLP) is the primary resource regarding communication issues and swallowing problems. The functions of the SLP include:

- Evaluating speech and communication status during ALS Center visits.
- Discussing communication strategies to preserve speech communication for as long as possible.
- Referring for full augmentative communication device evaluation as needed.
- Discussing swallowing skills and appropriate compensatory interventions.
- Consulting with clinic staff, families, and outside SLPs about communication or swallowing issues.

**SOCIAL WORKER:** Laurie B. Fieldman, LCSW, at 847-223-9889. E-mail marciesplacecamp@yahoo.com.

The Social Worker is a licensed clinical social worker (LCSW) who assists patients and families with a variety of issues. The functions of the social worker include the following:

- Talking with patients and/or families at clinic visits at the Lois Insolia ALS Center regarding any changes in physical health, emotional well-being, or job

situation. This may also include discussions in which the LCSW can provide information regarding Disability, Medicare, Medicaid, and private insurance, and financial resources.

- Assisting the family in maximizing assistance for care of the patient. This may include accessing care through state-assisted programs or hiring a caregiver with out-of-pocket resources.
- Providing counseling at the Lois Insolia Center to patient and/or family members.
- Making home visits for counseling with patients and/or family members. Counseling may be for an individual, a couple, or a group, such as a family meeting. These visits may be made on an on-going schedule, or on an as-needed basis.
- Consulting with parents and/or grandparents (at clinic, by phone, or in a home visit) regarding the emotional care of children in the family who are touched by ALS. The LCSW can provide guidance on how to talk with children of all ages about the disease throughout the entire progression.
- Making home visits specifically to work with children whose family member (usually a parent or grandparent) has ALS.
- Providing consultation to other professionals working with ALS patients/families.
- Providing bereavement support as requested by family members.
- Providing assistance with a living will, medical power of attorney and end of life issues.

### **SUPPORT GROUP FACILITATORS**

Laurie B. Fieldman, LCSW at 847-223-9889. E-mail [marciesplacecamp@yahoo.com](mailto:marciesplacecamp@yahoo.com).

Group facilitator in Elk Grove Village, Orland Park, and Libertyville.

Anne Lidsky, Ph.D. at 847-441-0202. E-mail [alidsky1@aol.com](mailto:alidsky1@aol.com). Group facilitator in Skokie. Anne has been with the Les Turner ALS Foundation for more than 20 years.

Ileane Mindel, RN at 312-255-9719. Group facilitator in Elk Grove Village, Orland Park, Libertyville, and Skokie.