

WE ARE WITH YOU

**Every Step of the Journey**



**The ALS Association Certified Centers<sup>SM</sup>**  
*Committed to Excellence in Multidisciplinary Care*

## OUR MISSION

To lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

# Table of Contents

## *Section 1: Center Information and Benefits*

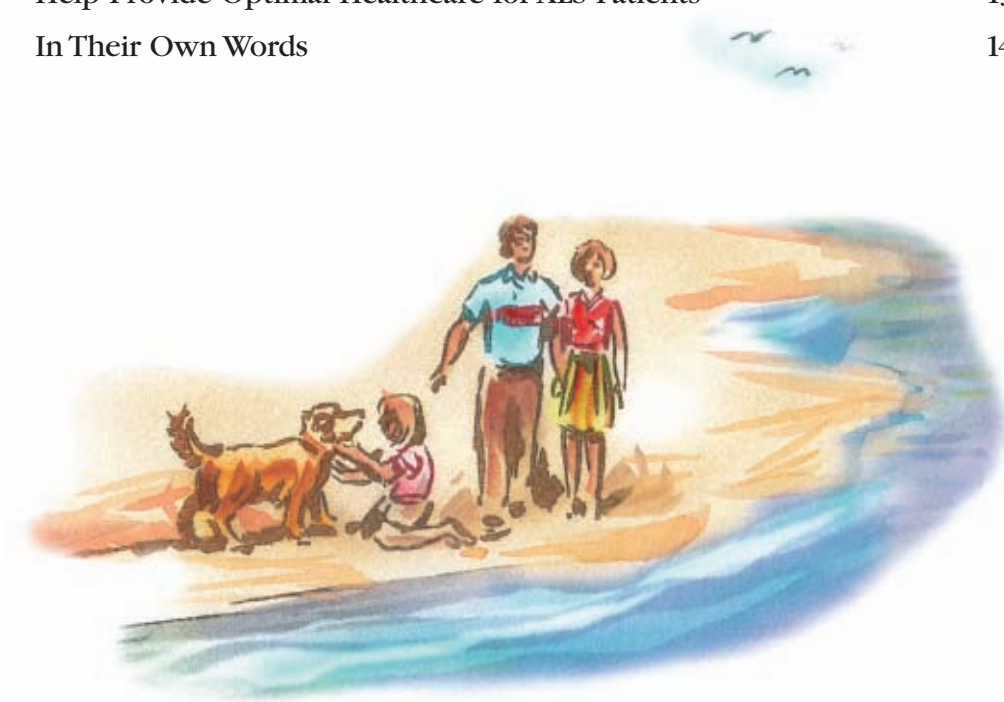
Out of the Blue	3
All-in-One Services	4
A Proactive Approach	5
A Positive Impact	6

## *Section 2: Team Approach*

Hallmarks of Center Care	7
A Typical Center Visit	8
The Value of the Team Approach	10
Q&A with Celeste	12

## *Section 3: Patient Participation*

Research and Clinical Trials	13
Help Provide Optimal Healthcare for ALS Patients	13
In Their Own Words	14



# Out of the Blue



## The bad news comes out of the blue.

An engineer in his fifties is playing an intense game of volleyball with his friends. Suddenly he trips and falls without good reason. A lifelong athlete, he later notices he's having trouble standing on just one leg when he's getting dressed.

A nursing supervisor at a hospital stumbles as she runs down the stairs – time and time again.

A geologist who travels a lot on business starts to feel his neck is unusually weak after a long flight. His arm and hand continue to get weaker on one side over the months that follow.

Soon there's a visit with a physician, then a neurologist, and some tests. Sometimes more doctors are called in to pinpoint the problem.

And then, there are these words:

*"I have some bad news. You have amyotrophic lateral sclerosis, ALS, also known as Lou Gehrig's Disease. It is a progressive, degenerative neurological disease resulting in weakness of voluntary muscles. The cause is unknown. There is much research being done, but at this point, we cannot reverse the progress of the disease. But we will be with you, supporting, helping and guiding you, every step of the journey."*

## What next?

First comes shock, fear and enormous adjustment, followed by a desire to get the best care possible from physicians and other healthcare professionals who are specialists in ALS. People with ALS want to find healthcare professionals who are committed to helping them maintain function and to ensure the highest possible quality of daily life.

That's when The ALS Association Certified Centers<sup>SM</sup> Program steps in and begins to play a significant role in the lives of people with ALS.

# All-in-One Services

**The ALS Association Certified Centers<sup>SM</sup>** specialize in the management, care and support of people with ALS, providing resources and clinical expertise that make it easier for patients to cope effectively with ALS and live the highest quality of daily life.

The Certified Centers do this by providing multidisciplinary care at a *single site*, so that people with ALS and their families can see a wide range of experts at each visit. Rather than going from department to department or office to office over several days, people with ALS receive well-organized consultations from a dedicated, centralized collaborative team representing the disciplines essential to their care.

The Certified Centers are selected, supported and regularly evaluated by The ALS Association. Each is a distinguished regional institution recognized as the best in the field for knowledge and experience with ALS. Every Center is under the direction of a neurologist specializing in ALS, with the support of a licensed and certified professional staff that delivers physical therapy; occupational therapy; respiratory therapy; nursing; registered dietitian services; psychology or psychiatry, speech and language pathology; and social work services.

Although ALS is a neurological disorder, its functional and emotional consequences require the expertise of many professionals. This is why the multidisciplinary team at The ALS Association Certified Centers is so crucial. Bringing these specialists together not only gives each patient the benefit of their breadth of expertise, but also fosters a team approach that is highly effective in solving problems and dealing comprehensively with issues that arise as the disease progresses.



## A Proactive Approach

**Patients who come to The ALS Association Certified Centers** are motivated by their desire to do all they can to deal effectively with ALS, says Eric Sorenson, M.D., Associate Professor of Neurology and Director of The ALS Association Center and Research Program at the Mayo Clinic, in Rochester, Minnesota.

“Patients who come to the Centers want to be proactive, addressing questions and problems before they arise and working with leading experts in ALS,” Sorenson says. “Having a team that works together – rather than seeing patients through separate visits in different locations and organizations – helps to ensure that specialists are addressing the big picture.”

This teamwork also ensures that each patient gets the care appropriate to his or her case. Every individual with ALS has a unique course and progression, explains Sorenson. “The psychological response to the disease, the speed of the disease’s progression, and its impact are different for almost everyone,” he says. “The ALS Association Certified Centers are designed to ensure that each person with ALS is connected to a dedicated team able to help the patient cope with the uniqueness of his or her experience, based on the team’s broad experience and expertise.”



**Eric Sorenson, M.D.,**  
Associate Professor of Neurology  
and Director of The ALS  
Association Certified Center  
and Research Program,  
at the Mayo Clinic, in  
Rochester, Minnesota

# A Positive Impact

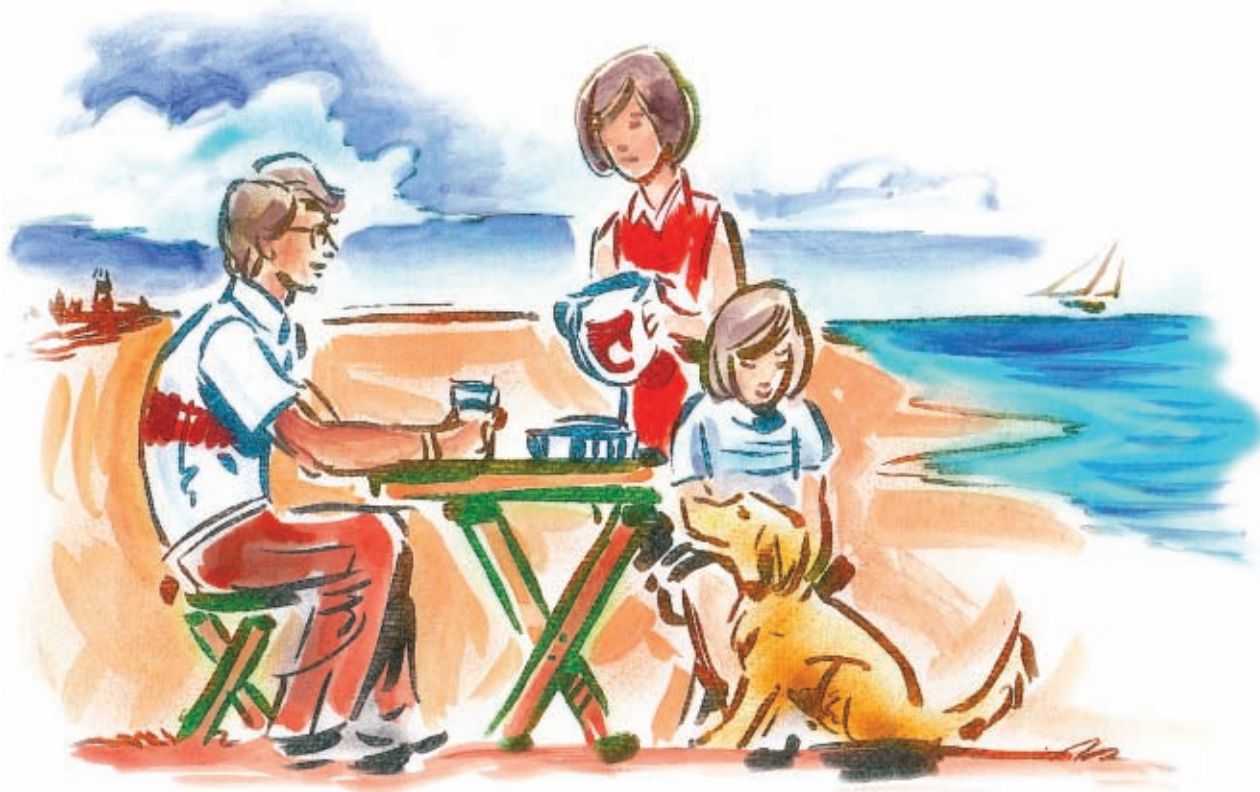
**Studies have shown that the multidisciplinary team approach** has a positive impact on a patient's longevity, extending life by six months or longer. In October 2009, the American Academy of Neurology (AAN) released new practice guidelines developed by a team of ALS experts. The guidelines say that ALS multidisciplinary clinics, such as The ALS Association Certified Centers,<sup>SM</sup> optimize healthcare delivery, prolong survival, and may also enhance people's quality of life.

"The Centers are the most comprehensive way for us to manage patients," says Todd Levine, M.D., Medical Director of The ALS Association Certified Center at the Banner Good Samaritan Medical Center in Phoenix, Arizona. "People who come to the Centers live longer and receive a personal and hopeful approach to their care, which is a hugely important aspect of what we do."

Levine says the Centers are committed to making life better for people with ALS, providing hope, support and solutions to the problems, and issues they encounter.



**Todd Levine, M.D.,**  
Medical Director of  
The ALS Association Certified  
Center at the Banner Good  
Samaritan Medical Center,  
in Phoenix, Arizona



# Hallmarks of Center Care

**Certified Centers are located throughout the United States.** Each reflects the personality and approach of the medical director and staff, and they use a variety of approaches in organizing and running the clinics. But all Certified Centers share these same essential features:

- **A collaborative multidisciplinary team** that works together to provide answers and solutions to patients and their families. This approach ensures that team members work closely together and consult each other regularly to help ensure the highest level of care possible.
- **Shared decision-making** between the patient and the team. The patient is considered a full and active participant in determining what approaches to care will be followed.
- The **patient's treatment decisions are respected** by the team. Patients and families are encouraged to ask questions, weigh alternatives, and express their thoughts about options.
- **Members of the multidisciplinary team are present at each visit** and are available to patients and families at virtually any time to answer their questions and help solve problems.
- Centers focus on maintaining function and treating symptoms to **help patients achieve the best possible quality of life.**
- The medical director is **involved in ALS research**, which can involve clinical trials.
- **Each Center is regularly evaluated** by an ALS Association committee whose members are all from Certified Centers and are familiar with the national standards of care.



**E. Peter Bosch, M.D.,**  
Medical Director of  
The ALS Association  
Certified Center at the  
Mayo Clinic in  
Scottsdale, Arizona

E. Peter Bosch, M.D., Medical Director of The ALS Association Certified Center at the Mayo Clinic in Scottsdale, Arizona, notes that patients who come to the clinics have already been diagnosed with ALS, so the Centers are dedicated to maintaining the patients' level of functioning and assisting them with their everyday activities. "And we offer people *hope*," he says. "That's very important."

In addition to helping people proactively deal with problems and identify issues early on, Bosch says, the Centers ensure that patients have someone they can personally call at the Center to get the answers they need right away.

# A Typical Center Visit

**Each person with ALS has a unique experience with the disease.** The ALS Association Certified Centers are designed to give patients and their families a regular, thorough and interdisciplinary evaluation; answers to their questions; and solutions to their problems.

Typically, a visit involves a full morning or afternoon and occurs about every three months. Prior to an appointment, patients may give an update on their situation over the phone to the clinic nurse, and they are sometimes asked to have blood drawn or a pulmonary function test before arriving at the Center.

Because staff members and patients get to know each other well over time, every Center has a warm, welcoming atmosphere. Staff members, patients and their families see one another as friends, and it shows in the conversations that are typical when patients return for one of their regular visits. People ask how last month's trip to see relatives went, whether a staff member brought a picture of her new baby, or whether the family is still planning the cross-country trip in the motor home. One patient says it feels like each visit to a Center is a "homecoming."

One by one, according to a carefully crafted schedule, members of the multidisciplinary team see the patient for evaluation and discussion. For example, a dietitian will talk about nutrition, compare the patient's weight to the last visit and discuss any issues that have come up in the meantime. The registered nurse will gather general information about how the patient is feeling and answer questions (the R.N. also helps coordinate care and facilitates any special consultations or follow-up care). From the respiratory therapist, the patient hears the results of his or her pulmonary function test and may discuss options for improving breathing both during the day and at night. With the physician, the patient's overall condition is assessed and discussed. Participation options



*Medical Director*



*Registered Nurse Coordinator*



*Speech Language Pathologist*



*Occupational Therapist*





*Social Worker*



*Chapter Liaison*



*Physical Therapist*



*Dietitian*



in clinical trials may be discussed, or outpatient tests may be recommended.

The speech therapist may talk about communication devices that the patient and family might want to consider in the future. The physical therapist could help a patient learn to use a cane properly for support, or may reconfigure a hand control on an electric wheelchair. A representative from The ALS Association may talk about the monthly support group or offer free, available equipment that another team member may have recommended to the patient. The social worker may help in handling an insurance reimbursement problem or suggest a counselor for a teenage daughter who is having difficulty dealing with her parent's diagnosis. An occupational therapist may suggest new silverware or a specially-designed plate to make eating much easier.

After the patient and family go home, the entire staff gathers for a valuable team meeting and reviews problems and solutions to help ensure every possible approach has been considered for each individual patient. The team then sends the patient its recommendations from the day, with a reminder to call anytime questions arise.

"Patients tell me that they like to come to the Center because they know there are people looking out for them and there is a team that is experienced with ALS," says Kathie Vanderpool, R.N., at the University of Kentucky, ALS Association Certified Center, in Lexington. "It's a very individualized approach and people feel they're in a place they can come and be themselves. And we give patients time. We are not in a hurry; they spend several hours with us and get their needs fully met."



**Kathie Vanderpool, R.N.**, of The ALS Association Certified Center at the University of Kentucky in Lexington, Kentucky

# The Value of the Team Approach

**There are many challenging diseases**, of course, but only a handful need the multidisciplinary, highly-coordinated, regular care that ALS requires. That's because ALS is a complicated, progressive disease that involves many of the body's systems. One problem can have a direct bearing on another, and solutions have to take into consideration the patient's total situation. Some of the necessary problem solving requires **creative thinking based on the insight and experience of professionals from several disciplines at once.**



**Mark Ross, M.D.**,  
Medical Director of The ALS  
Association Certified Center<sup>SM</sup>  
at the Mayo Clinic in  
Scottsdale, Arizona

"ALS patients have multiple problems and need input from specialists and many disciplines," says Mark Ross, M.D., Medical Director of the Mayo Clinic in Scottsdale, Arizona. Having the team working together, with its members fully accessible to one another and to the patient, makes solving problems far easier, he says.

The team approach also is highly efficient because it **keeps problems and issues from falling through the cracks.** If a patient mentions a problem to one team member who may not know a solution, the issue can easily be referred to another member who can solve it. Team members compare notes with each other throughout the clinic day and at a team meeting at day's end, thus ensuring that each patient's situation is thoroughly understood and the right approaches are chosen to deal with it.

Team members also benefit from working closely with each other, says Dr. Ross. "I learn things all the time from members of the team. We also find that **the team approach reinforces the dedication everyone has in supporting this illness.**"



**Edward Kasarskis, M.D.,  
Ph.D.**, Medical Director of  
The ALS Association Certified  
Center at the University of  
Kentucky in Lexington, Kentucky

The team approach also helps patients sort out their priorities and understand what problems should be addressed, frequently even before they occur. "We provide **reliable, credible, broad guidance,**" says Edward Kasarskis, M.D., Ph.D., Medical Director of the University of Kentucky ALS Association Certified Center.

By offering such a wide range of experience and expertise, the team also is able to **identify problems quickly and thoroughly.** "The respiratory therapist might hear from a family member that the patient is having trouble navigating the house and recommend that the occupational therapist evaluate options," says Bernie Miller, R.T., at the Mayo ALS Clinic in Scottsdale, Arizona.

The team is inspired by the patients and **committed to doing all they can to make their lives better,** says Miller. "We're attached to each other." An ALS Association Chapter is affiliated with each Center. A Patient Services staff member participates in the clinics,

talks with patients and staff, and makes a broad range of free equipment available as needed.

The Chapter also provides information, answers questions, holds support groups for patients and caregivers, and provides numerous at-home services, such as respite care. **"We work hard to help people use**



**Bernie Miller, R.T., Ph.D.**,  
of The ALS Association  
Certified Center at the Mayo  
Clinic in Scottsdale, Arizona



**Kim Hughes, Director  
of Patient Services**, The ALS  
Association Arizona Chapter

**their financial resources where they need it most**, and we provide help on the details of insurance, Medicare and Medicaid,” says Kim Hughes, Director of Patient Services for the Arizona ALS Association Chapter. “The team collectively makes a huge difference in their families’ lives and really cares.” The Chapter helps ensure the patient and family are part of the larger community that is committed to supporting people with ALS and their families in a broad variety of ways.

Lakshmi Joshi Boyle, M.S., C.C.C.-S.L.P., a certified speech and language pathologist at the ALS Clinical Department of Neurology at the University of Vermont College of Medicine, adds, “We bring humor, hope, a positive approach, and offer practical solutions.”

Because patients make regular visits and see the entire team each time, the Centers foster strong relationships between the patients and their families and the team. **“We develop a rapport and establish trust with each other**, and that’s a really strong component in caring for a person with ALS,” says Marcia Larson, R.D., C.D.E., a registered dietitian at The ALS Association Certified Center at the Mayo Clinic in Scottsdale, Arizona. “It gives them hope and power to know the whole team is working on helping them,” says John Bargas, P.T., a physical therapist at the Banner Good Samaritan Regional Medical Center of The ALS Association Certified Center, in Phoenix, Arizona.



**John Bargas, P.T.**, of The ALS Association Certified Center at the Banner Good Samaritan Regional Medical Center in Phoenix, Arizona



**Lakshmi Joshi Boyle, M.S., C.C.C.-S.L.P.**, of The ALS Association Certified Center<sup>SM</sup> at the University of Vermont College of Medicine, in Burlington, Vermont

Center staff members are dedicated to giving **highly personalized, individualized care**. “We don’t have a template we try to plug people into,” says Judy Crouse, M.S.W., at The ALS Association Certified Center at the University of Vermont College of Medicine. “We listen, we are very creative, we do home visits – whatever the patient needs – and we include the family and support system.”



**Judy Crouse, M.S.W.**, of The ALS Association Certified Center at the University of Vermont College of Medicine, in Burlington, Vermont

Then there’s the enormous benefit of receiving care from **a team of people who specialize in ALS**. “You don’t want to be the third case in a year; you want to be the fourth in a day,” says Dr. Kasarskis.

Gretchen Daly, an occupational therapist at The ALS Association Certified Center at the University of Vermont College of Medicine, sums up the strengths of the team approach: “When you have ALS, it’s all about quality of life and identifying your priorities. The team works to help patients maximize their resources and abilities to live the life they want to live.”

## Q&A with Celeste

**Interview with Celeste Mullenex, a patient at The ALS Association Certified Center at the University of Kentucky in Lexington.**

**How do you find The ALS Association Certified Center helpful to you?**

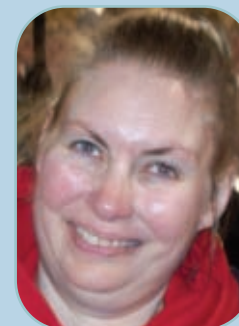
For the first one-and-a-half years after my diagnosis, I wasn't part of a clinic and was seeing just a physician. I thought I didn't need any other help. But on my first visit to the clinic, the staff asked about any problems and I mentioned my inability to use the computer keyboard due to weakness in my arms. The occupational therapist showed me how to use the accessibility options to type with the onscreen keyboard. I felt like this reconnected me with a whole world I had been missing terribly. I left the clinic that day very happy. My only regret was that I hadn't gone sooner.

**How does the team approach help you?**

If I ask one person a question that isn't in their field, they discuss it and send the right person back in to see me. I don't have to wait for answers or make more than one trip.

**How does The ALS Association representative make a difference?**

It's so important to have that one person who gives you her card and, when she says, "Call with any questions," you know she really means it. It's like having a lifeline when you're lost all alone in a stormy sea. That is what you feel like when you're diagnosed with ALS.



Celeste Mullenex

**How does the Center experience help Shawn, your husband?**

The staff praises us both for our great attitudes and obvious love for each other, and for the great job Shawn does taking care of me. That's good for him to hear from someone besides me.

**Do you feel the staff is truly expert in the care of people with ALS?**

I feel the clinic is so important because you are seeing people who are specializing in ALS. They may treat 30 ALS patients a month, so they are extremely familiar with the disease and how to treat the problems that arise.

**Do you feel like part of the team, rather than just a patient?**

I've spoken with other patients about this and we all agree we're treated like celebrities. The staff seems genuinely excited to see us and very happy about the strength we've maintained. These visits could be quite depressing, but the staff makes the day feel like a get-together with friends.

**Clinical research is an important part of each ALS Association Certified Center.** Not only does the work make a huge contribution to the collective global knowledge about ALS, but it also frequently provides opportunities for people with ALS to personally participate in clinical trials.

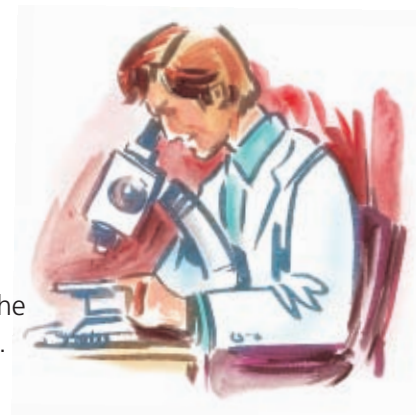
By being active in current research activities, the Centers are at the forefront of best practices in ALS treatment and drug therapy. Information gained from research is shared directly with patients to help them gain greater insight into the nature of ALS and to learn about new therapies and approaches to the disease.

In addition to the research, medical directors of the Centers are involved with national and international research teams and consortia. The Northeast ALS Consortium, for example, currently has more than 80 research members stretching from coast to coast. Some Center directors work with such organizations as the National Institutes of Health on review panels that help delegate funds through congressionally-supported research for ALS and other related disorders.

At The ALS Association Certified Center at the University of Vermont College of Medicine, for example, Medical Director Rup Tandan, M.D., F.R.C.P., conducts three or four ongoing studies at a time. "For patients, it is gratifying to be doing something to combat the disease. And, for physicians and staff, research is essential to slowing the progression of ALS and finding new approaches to treatment," he says.



**Rup Tandan, M.D., F.R.C.P.**, Professor, Vice Chairman and Medical Director of The ALS Association Certified Center at the University of Vermont College of Medicine in Burlington, Vermont



## *Help Provide Optimal Healthcare for ALS Patients*

**While ALS is an expensive disease to treat, the multidisciplinary care offered at ALS Association Certified Centers has been proven to provide a wide spectrum of benefits to patients, payors and the entire healthcare community:**

Recent studies demonstrate the positive impact of Center-based care on longevity.

Broad anecdotal evidence substantiates that the well-choreographed team approach provided at the Centers increases efficiency and improves outcomes, resulting in the highest possible quality of life for patients and reduced overall costs of care.

Research conducted at the Centers provides patients with the opportunity to participate in clinical trials that can result in improved care for all people with ALS.

Patients interested in receiving care at an ALS Association Certified Center should contact the Center staff.

Your generosity can make a meaningful difference in the lives of ALS patients and those who love them.

To find out how you can help provide optimal care for people with ALS through a gift in support of The ALS Association Certified Centers, please contact The Association's Development Department toll-free at 888.949.2577.

# In Their Own Words

**Patients are at the center of the care** The ALS Association and its network of Certified Centers provide. Physicians and staff are here to help people with ALS and their families every step of their journey with excellent care, multidisciplinary resources, and a commitment to be with them whenever needed.

Here are some thoughts from patients and their spouses:



**Robert Prevost**

*“When Robert first was diagnosed with ALS, we obviously were in shock and a little bit of denial, and we started feeling sorry for ourselves. But the people at the clinic gave us hope and helped us live day by day and just keep plugging away. They focus on what you can do. They stay upbeat, keeping a positive attitude and keeping us positive as a result.”*

**Ginny Prevost**

wife of ALS patient Robert Prevost  
Arizona

*“I believe in being proactive in dealing with problems. Being involved in the clinic helps you be in control of the situation and prepare for changes before they occur.”*

**Dennis Hoyniak**

ALS patient  
Vermont



**Dennis Hoyniak**



**Celeste Mullenex**

*“What I find most helpful from the staff is that after my visit to the clinic I receive a form in the mail with a note from each discipline reminding me of their recommendations. This is important because I always see something I’d already forgotten! It is so great to see so many specialists in ALS in just one trip.”*

**Celeste Mullenex**

ALS patient  
Kentucky

## ABOUT THE ALS ASSOCIATION

In the quest to create a world without ALS, our vision is to care for and support all people living with Lou Gehrig's Disease as we leave no stone unturned in our relentless search for a cure.

We provide a wide range of services, including research, patient services, advocacy, public education and community services. For more information, call 818.880.9007.

For an updated list of The ALS Association Certified Centers, visit the web site at [alsa.org](http://alsa.org) or phone **800.782.4747**.



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