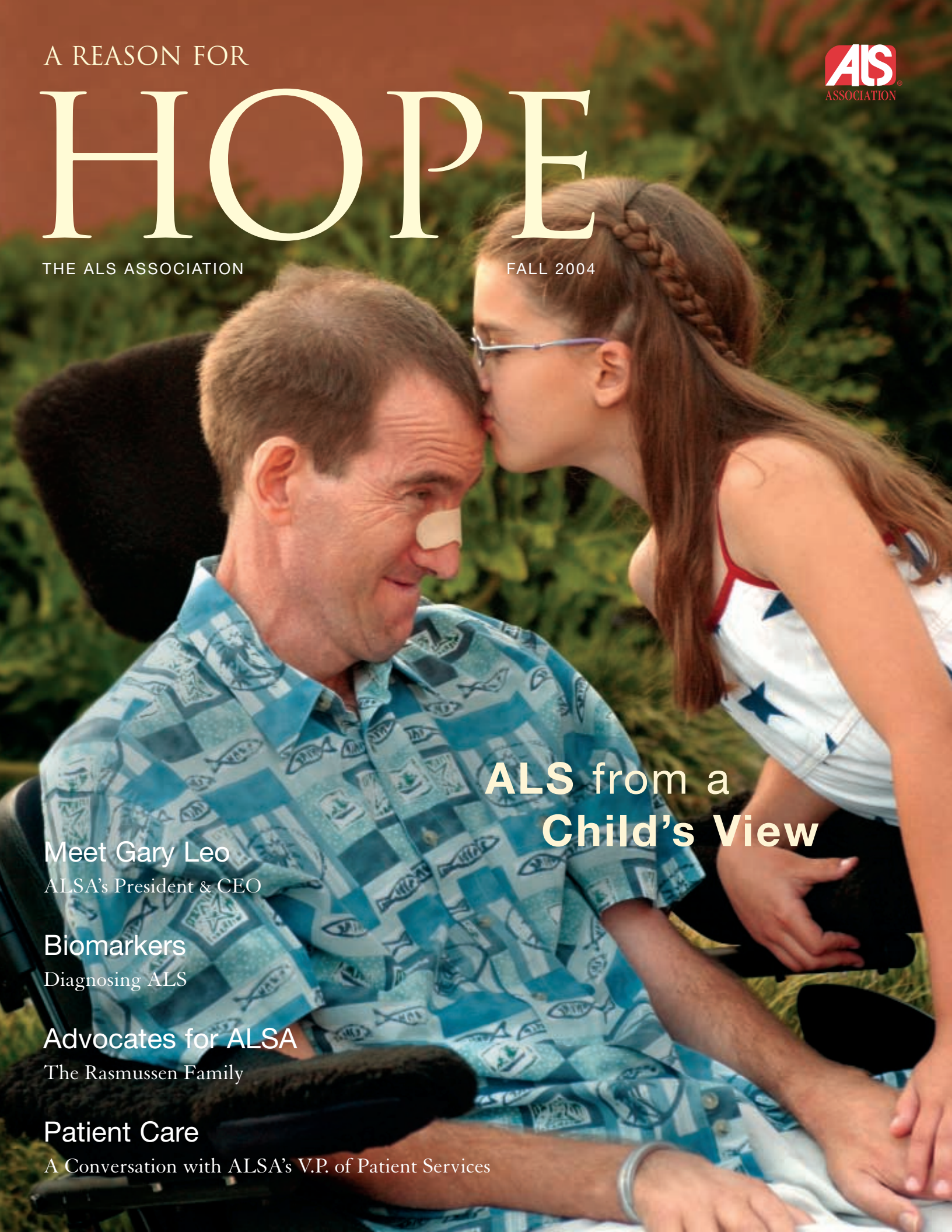
A REASON FOR

HOPE

THE ALS ASSOCIATION

FALL 2004



ALS from a Child's View

Meet Gary Leo
ALSA's President & CEO

Biomarkers
Diagnosing ALS

Advocates for ALSA
The Rasmussen Family

Patient Care
A Conversation with ALSA's V.P. of Patient Services

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HOPE

TABLE OF CONTENTS

1 | Gary Leo
A Catalyst for Action

2 | Growing Up With ALS

4 | Caregivers
Take Care of Yourselves

5 | Patient Care
Past, Present and Future
A Conversation with ALSA's
Vice President of Patient Services

8 | Biomarkers
Searching for an Accurate
ALS Diagnosis

10 | Dean and Kathleen Rasmussen
Working in Partnership to
Find a Cure for ALS

12 | Living With ALS
The Importance of Being Me

13 | William's Story
Tribute to a Real Fighter

ABOUT THIS ISSUE... The purpose of A Reason For HOPE magazine is to cast a revealing light on subjects foremost in the minds of people who are living with ALS and their families, loved ones and caregivers. A major focus of this issue is patient and family care.

Our cover story, which is actually three stories, delves into the tender relationship between a child and a parent with ALS. Though their eyes, we witness a child's perspective of the disease that has become an uninvited participant in their young lives.

From a professional woman, a wife, a mother and an ALS caregiver, we are allowed an intimate glimpse into how a family is affected by the realities that accompany this disease. Also in this issue, HOPE spoke with Mary Lyon, ALSA's vice president of patient services, about the past, present and future of ALS patient and family care, and she shares her insights into developments in therapy, devices helpful to patients and ALSA's comprehensive approach to caring for those impacted by ALS.

HOPE visited with Dean and Kathleen Rasmussen, who dedicate a large portion of their time and resources to finding a cure and advocating on behalf people with the disease to help them live better. In our "Living With ALS" section, a registered nurse reveals how she continues to live a full life in spite of her physical challenges.

The content in this issue of HOPE magazine is designed to be informative and useful. As always, we invite your comments and suggestions regarding the publication. HOPE is available on ALSA's web site, http://www.alsa.org, and through e-mail distribution. To subscribe, visit http://www.alsanews.org and follow the instructions.

Greg Cash
Editor & Director
Communications

On the cover: Pictured on the cover are Brooke Conlin and her father Gary, who are featured in the article "Growing Up With ALS." The photograph was provided by Wesley Kong.

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GARY LEO
A CATALYST FOR ACTION

By Dan Gordon

Gary A. Leo, President and CEO

When it comes to charting his career course, Gary Leo, The ALS Association's new president and chief executive officer, follows a simple philosophy: "Define what you enjoy doing in life and then find someone who will pay you to do it," he explained, smiling. For Leo, enjoyment comes from knowing he is making a difference. "I know it sounds corny, but for me what's important is to use my abilities and personal drive to accomplish something that leaves the world a better place," he said.

Leo's social conscience and upbeat nature have guided him through more than three decades in non-profit management, fundraising, teaching and training – most recently as senior vice president for development at Cedars-Sinai Medical Center in Los Angeles, one of the largest non-profit academic medical centers in the Western United States. While garnering resources to support an organizational mission has always been a major part of his job description, Leo likes to view his role not as a fundraiser but as a dream-maker. "People have visions of making a difference," he said, "and I help them to fulfill those dreams."

"We want to do whatever it takes to expedite the process of finding answers."

Leo got his first up-close glimpse of the devastating nature of ALS more than two decades ago, when he met former Sen. Jacob K. Javits, the legendary New York politician who at the time was courageously fighting the disease. "Here was this larger-than-life figure, a charismatic leader of great oratory skills, who needed every bit of energy in his body to make his way up to the platform and speak," recalled Leo, who was working at a book fair where Javits was delivering the keynote address. More recently, a man who has been a mentor and dear friend to Leo was diagnosed with ALS.

When he met with the Association's leadership prior to his appointment, Leo knew this was where he wanted to be. "There was such a passion and dedication among people who viscerally understand how this disease affects individuals and their families and friends," he said. "And at the same time, I saw the incredible courage of ALS patients in being able to cope with the disease and maintain their sense of humor under the most adverse conditions. Finally, I saw a professional staff that couldn't wait to come to work every day. It was all so inspirational. Who wouldn't want to be part of something like that?"

Leo, who holds a bachelor of arts degree in economics from Queens College, a master's degree in educational administration from New York University and a master's degree in social work administration and planning from Rutgers University, has responsibility for the strategic direction and operation of ALSA, which directs the largest privately funded research program into ALS and includes The Association's nation-wide network of chapters that deliver an array of services to patients with ALS, their families and caregivers. At the national level, Leo oversees The Association's activities in research, advocacy, finance, development, community services, patient services, communications, management and operations.

"People have visions of making a difference, and I help them to fulfill those dreams."

Among his immediate goals is to continue to strengthen and expand the network of ALSA chapters so that more ALS patients can receive critical services. Leo will also focus efforts on generating more funding to support research, partly through education and advocacy to mobilize public and private funding that will encourage talented investigators to pursue exciting new avenues of ALS study. Toward both of those goals, he intends for ALSA to serve as a catalyst for strategic partnerships among organizations with an interest in ALS research and patient services.

"We want to do whatever it takes to expedite the process of finding answers," Leo said. "The only thing holding us back from accomplishing our mission is more resources. But the good news is that we're moving in the right direction."

Indeed, Leo likes to emphasize that despite the dreadful disease afflicting ALSA constituents, The Association's activities are infused with hope. "This is a good-news organization," he said. "Every day, we're coming up with new modalities that extend patients' lives. Every day, we're finding new ways to help patients and their families cope. And every day, we're supporting studies to learn more about this disease so that we can one day stop it in its tracks."

Photos by Thomas Neerken

GROWING UP WITH ALS

By Katie Sweeney

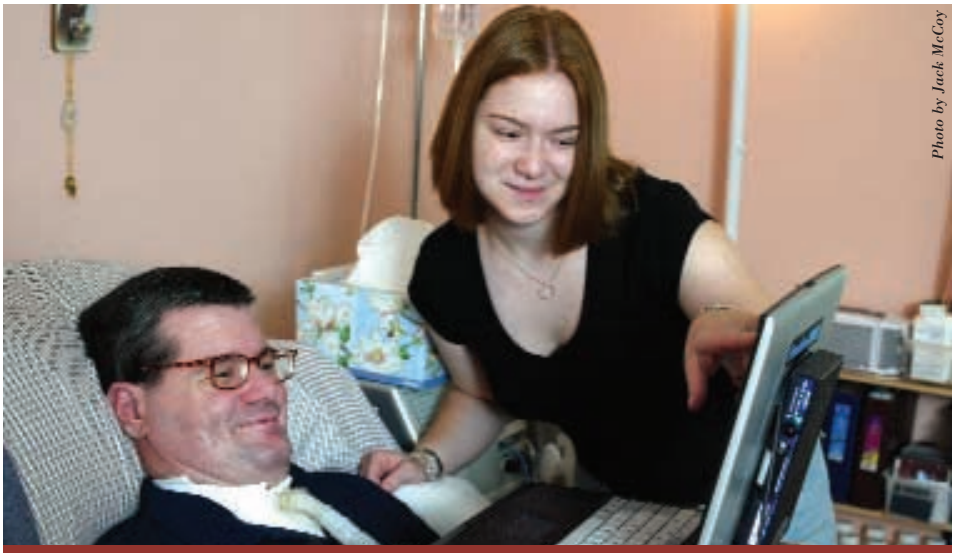


Photo by Jack McCoy

Christina and Anthony Raia

It's not easy having a parent with ALS. But with support, attention and love, children and teens can – and do – learn to cope.

Growing up, Christina Raia was always close to her father. As a little girl, she would run to him when he arrived home from work, and he would lift her up and swing her in the air. He would drive her to dance class and take her to the bakery for a treat on the way home. When she struggled with her sixth grade honors math class, he refused to let her give up, patiently helping her with her homework every night.

These days, though, it's Christina who is helping her father and refusing to give up. Ever since her dad, Anthony, was diagnosed with ALS five years ago, Christina has poured her energy into raising money and awareness for the disease. This 19-year-old college student and her family have raised $45,000 for ALSA's Greater New York Chapter.

Taking action is what's helped her deal with her father's illness. "It's rough," admits Christina, who was 14 when her dad was diagnosed and is the oldest of five children. "I probably cry a couple of times a week. Basically, what's kept me going is getting involved."

Coming to terms with ALS isn't easy for anyone, and it can be especially tough to watch a parent go through the disease. But kids, just like adults, can learn to cope – and parents can help them.

"A lot of times, parents don't know how to talk to children," says Jennifer Brand, director of chapter patient services for ALSA's national office. "They think maybe it's better if they don't know anything. But children do need to understand in a way that's appropriate for them."

"That's Not Fair!"

Twelve-year-old Michael Swinnen can't remember a time when he didn't understand that his father has ALS. That's because his dad was diagnosed at age 28 – before Michael was even born.

At the time, Michael's parents, Terry and Marijo Swinnen, had been married for five years and were undergoing infertility treatments in an effort to have their first child. When Terry's disease began to progress, they decided to stop trying for a family. Two weeks later, Marijo was pregnant. After Michael was born, they decided to have a second child, and Zachary arrived soon afterward.

Even as preschoolers, the boys knew that their dad had ALS, and that one day he could die. The topic was never taboo.

"Sometimes the boys wouldn't understand why we couldn't do things, and we would have to say, 'It's because your dad's in a wheelchair,'" Marijo says. "And they would say, 'That's not fair!' And then we would talk about things being fair in life. We didn't feel that hiding things from the children to protect their feelings was a good thing."

Terry has had ALS for 15 years, but that hasn't stopped him from being an involved father to his sons. A former high school and college athlete, Terry gives Michael and Zachary pointers on baseball, football and basketball. He and Marijo even helped coach Michael's basketball team last year.

ALSA offers a variety services to help children who have loved ones with ALS. Programs vary from chapter to chapter, but can include:

- Referrals for individual and group counseling
- Case management
- Support group referrals
- Library of books for parents
- Activity books for children
- Pen pal programs
- Special kids-only events
- Summer camp vouchers

Terry, Zack and Michael Swinnen

So what's it like to grow up with a dad who has ALS? Michael admits it makes him sad sometimes. But, he adds, "Really, most of the time, we don't think about it. Whenever you do, you kind of feel like you want to have a dad who can play catch with you out in the front yard or pitch to you in the batting cage. But it usually doesn't bother me that much."

Keeping the Faith

Brooke Conlin also gets plenty of help with her softball skills from her dad, Gary. Gary is in a wheelchair, but has verbally directed Brooke, 9, and Shane, 8, as they learned to play sports.

Brooke, a fourth-grader whose smile reveals a row of bright blue braces, easily recites her dad's instructions: "Turn your shoulder when you throw. Drop your front elbow when you bat. Follow through with your throws." She apparently took his advice. This year, she was voted "most improved player" on her team.

"If you watch them, you would have no idea what these children are going through," says Maria Conlin, mother of Brooke and Shane. "They're genuinely happy, joyful kids."

That doesn't mean it's easy. Brooke's eyes well up when talking about her dad's recent move to a nearby convalescent hospital. "The day he went to the hospital was the toughest," she says. That day, her best friend, Tiffany, gave her two bracelets and a big chocolate brownie.

Gary and Brooke Conlin

Maria credits the family's faith in God – and their willingness to talk openly about ALS – with helping them through the tough times. After Maria quit her job to care for Gary, friends from their church in Santa Fe Springs, Calif., stepped forward to pay their health insurance and even her former salary. Since Gary was diagnosed six years ago, he and Maria have talked openly with Brooke and Shane, giving them more information as Gary's disease became more visible.

Brooke likes to draw pictures and make cards for her dad. Her advice to other children who have a parent with ALS is simple. "Trust in God," she says. "Talk to your mom and dad. And have fun."

Editor's note: On September 17, Gary Conlin passed away. The ALS Association extends its deepest sympathy to the Conlin Family.

Helping Kids Cope

So how can parents help children? "The No. 1 rule is to be open and honest, and give information in an age-appropriate way," says clinical psychologist Jennifer Druke who is the patient services coordinator for the Orange County Chapter.

For example, young children may believe they somehow caused their parent's disease, that they can catch it themselves, or that they can make it disappear by "being good. Preschoolers can be confused by euphemisms for death such as "going to sleep."

"Elementary school children tend to worry about other people in their lives dying," Druke adds. "They may try to be 'perfect children' and put their own needs on the back burner."

Teenagers, meanwhile, are less confused by ALS, and therefore, have a more emotional response to it, says Katie Peterson, patient services coordinator at the San Francisco Bay Area Chapter. They're also most at risk for depression.

Keeping a sense of normalcy is helpful for kids of all ages, Peterson adds. Maintain regular rules and routines, if possible, and make sure that children have outlets for self-expression – and fun.

"Writing, drawing, music and sports all provide an opportunity for kids to do something they enjoy," Peterson explains. "It's a stress reliever for them and a great way for them to communicate how they're feeling. A child may not be able to say, 'I'm sad about this,' but it will come through in a drawing."

Parents should understand that children and teens will likely act out or withdraw in some way, Druke says; however, if you see prolonged or dramatic changes in a child's eating or sleeping patterns, significant behavioral issues or a big change in school performance, seek professional help.

While talking is important, taking action can help, too. Last year, the Swinnens helped organize the first Walk to D'Feet ALS® in their hometown of Mount Vernon, Ill. Michael and Zachary walked with the team and helped promote the event at school.

For Christina Raia, raising money and awareness for ALS has given her a sense of hope – and helped her grow as a person. Before her dad's diagnosis, she dreaded public speaking. Now, she speaks out about ALS as often as she can, and even gave a speech in front of her local legislature about the need for government funding. Next year, she plans to attend National ALS Advocacy Day.

"I think I kind of surprised (my dad)," she says. "I don't think he thought I would get as involved as I did…The only thing that would make me stop is a cure."

To learn about programs and resources available in your area, visit ALSA's web site at http://www.alsa.org or call (800) 782-4747 extension 218.

For online information about talking with children about serious illness and death, check out Hospice Net at http://www.hospicenet.org and The ALS Society of Canada at http://www.als.ca.

CAREGIVERS – TAKE CARE OF YOURSELVES

By Barbara J. Dickinson

About the author: Barbara Dickinson is the Director of Alumni Affairs at Brown University, a national trustee of The ALS Association and a former caregiver.

The patient is not the only victim of ALS. Sadly, the disease deeply affects caregivers, too, and even friends who are not on the front line. There is no disguising that caring for someone with a debilitating disease like ALS is taxing and exhausting. Caregivers need to understand that the emotions they experience are normal. They need to find ways to take care of themselves, even at the risk of feeling guilty or selfish.

During the ten years that our sons and I cared for my husband, I often felt angry, despairing, and guilty. I was not surprised to be in despair. I was deeply frightened and anxious, afraid for myself, my husband Brian and our sons. What was going to become of me? Could I carry on, would there be enough money, where would I find enough help? Were Brian and I, him through illness, me through neediness, irrevocably damaging our sons and limiting their futures?

I was often angry, as were we all. I was mad at a medical system that blithely said, "the family can take care of this," whether it was replacing a G-tube (feeding tube) or adjusting ventilator settings or diagnosing incipient pneumonia. Brian was demeaned by his illness, and he was often impatient. Our sons were furious that their adult lives seemed to be on hold. And every day, the workload increased. I was always so tired.

"We learned to value the small pleasures of life."

And guilt–guilt was my name. How could I be angry or tired? I could walk and talk and eat and breathe on my own. I wasn't dying. I had help and resources. So why couldn't I do more, give more, be less selfish, be less impatient and less sick of sickness. Why did insignificant things trouble me? It was clear to me that I was not a good person, and yet any criticism destroyed me. My tombstone would read: "She did her best, but it wasn't good enough."

ALS took a lot away from us. First of all, despite our best efforts, Brian died. We inhabited a world of illness where crisis became the norm. We gave up our privacy, as more and more health care personnel joined us in caring for Brian. Our house became a hospital of sorts. We are not healed completely from our experiences, physically or emotionally, and perhaps we will always carry with us the effects of ten years of stress and grief.

But, ALS leaves legacies that are unexpected. We each learned what we were, good and bad, and we learned to be tolerant of each other's failings. We gained perspective. We learned to value the small pleasures of life and to laugh at its general absurdity as well. We are now stronger, more generous, more patient as a result of our experiences. We are a tight family, understanding and supportive of one another.

After all, we did cope. Our sons finished their educations, got jobs, and got married during Brian's illness. Two grandchildren were born. I continued to work. We gave holiday parties, we visited with friends, we went on excursions. We tried for normalcy. We had time to talk and to reflect. We learned to negotiate, to manage, to cooperate. We know that we helped Brian live a productive and comfortable life with ALS; we did all we were capable of, and we are proud of that. And we are pretty sure that we can now handle just about anything that life throws at us.

"You must find ways to be good to yourself."

What helped each of us the most was stepping out of the situation whenever possible. Caregivers often feel guilty about taking any "R & R" for themselves, but they must. The most important advice I received when my husband was first diagnosed was, "A lot of people will be taking care of Brian, and no one will be taking care of you. You must find ways to be good to yourself." Caregivers, take care of yourselves. Accept all the help you can get. Schedule yourself free time. You will be better off, and so will the patient. And forgive yourself. You are doing the best you can in the hardest job you'll ever have.

For more information about caregiving, please visit us at: http://www.alsa.org/patient/facts.cfm

Patient Care Past, Present and Future

A Conversation with ALSA's Vice President of Patient Services

Mary Lyon, R.N., M.N.

Mary Lyon's work as a critical care nurse brought her into direct contact with people with ALS. Holding both a bachelor's and master's degree in nursing, she later moved from bedside nursing into management and education, serving as Vice President of Nursing Services for St. John's Hospital and Health Center in Los Angeles and Associate Dean for Administration at UCLA's School of Nursing. She came to The ALS Association in 1998, bringing her diverse experience to bear on shaping ALSA's internationally-recognized patient services program. Lyon spoke with HOPE about the past, present and future of patient care for the ALS community.

HOPE: How has caring for people with ALS evolved over the years?

LYON: In the past, it was common for people to hear a diagnosis of ALS followed by the admission that not much is known about the disease, we don't know the cause, there are no effective treatments, and future doctor appointments are unnecessary – basically, "get your affairs in order." Today, this conversation, fortunately, happens far less frequently because there is a great deal that can be done to help people live with ALS. In 1999, an important change occurred, the development of practice parameters or guidelines http://www.alsa.org/files/pdf/practice_parameter.pdf for the care of people with ALS. The guidelines are based on the medical evidence from studies about interventions and care that were beneficial to people with ALS. For instance, they focused on how to present the diagnosis. This guideline recommended conveying hope, talking about clinical trials and treatment approaches and describing the commitment from the medical profession on non-abandonment. In other words, that there would be a partnership between the healthcare providers and the patient and family throughout the course of the disease. Today, quite a lot can be done to help people with ALS.

HOPE: Tell us about the advances in clinical care responsible for transforming our view of living with ALS in recent years?

LYON: Clinical care in ALS has changed dramatically over just the past several years, primarily due to technologies that we have for breathing problems, nutrition, mobility and communication. Also there's been a major change in the attitudes of many within the ALS community: clinical practitioners, patients, and families – one that really is focusing on living with ALS, fighting the disease, looking for ways to manage care, to maximize function and maintain independence and control throughout this devastating disease. From that effort, the multi-disciplinary team and the concept of an aggressive approach to managing the symptoms of ALS have expanded. For many, seeing ALS as a chronic disease that can be managed offers a new, powerful perspective.

HOPE: Describe ALSA's patient services approach.

LYON: Part of The ALS Association's mission is to improve living with ALS for the patients and families who are fighting this disease. To achieve this, we use an approach called "ALSA Delivers." Through our network of 40 chapters, 19 certified centers, and 19 clinics working with chapters, we provide a comprehensive and intensive set of programs and services to support the needs of people with ALS and their families.

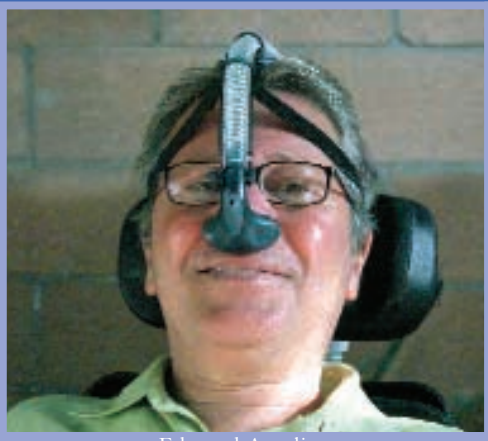
HOPE: What makes ALSA's services unique?

LYON: There are several hallmarks of The ALS Association's program of patient services. Key among them is the caliber of our staff and volunteers. ALSA's chapter patient services are staffed by healthcare professionals, each with a track record of service, dedication and a wealth of knowledge and skills to deliver the programs and services of The Association. Another hallmark is the comprehensiveness of the services that we provide. Certainly fundamental is the information and resource services, including telephone hotlines, e-mails, web sites, and educational materials that are available in print, electronically, multimedia and video. For practically every conceivable issue that a person and their family would be facing, we have educational tools to help. The ALSA Center Program provides certification to select ALS clinics who meet our criteria. These certified centers of excellence provide the leading clinical care and services for patients and families. The ALSA Centers and ALS clinics in our network have close relationships with local ALS chapters to coordinate services and assure continuity of care throughout the community into the home. Each person with ALS deserves to have complete and authoritative information. Our job is to provide the right information at the right time. Another fundamental program is our support groups. Chapters offer multiple support groups in various locations. Some chapters offer individual support groups specifically for caregivers, families or people that are newly diagnosed with ALS. Chapters offer formal and informal in-service education programs to individuals and groups who provide equipment and services for people with ALS including hospice, home health, and equipment vendors. Other programs include "Ask the Experts" or educational symposiums that are held once or twice a year, sometimes for healthcare professionals such as people from hospice or homecare, and in other cases for patients and families. This draws not only expert clinicians, but researchers who talk about what's new in ALS research. We have a one-of-a-kind clinical management grant research program, for stimulating ALS clinical management research. Offered by many of our chapters, our respite care program is vital in the support of caregivers and patients; this is unique to The ALS Association. "Home visits" is another program available at many chapters. In this program, staff and volunteers come into the home and provide information, support, follow-up on the medical management from the clinic, and equipment. In addition, they perform an assessment for respite and suggest environment improvements to make the home safer for the patient.

HOPE: What kind of progress have we made in patient care?

LYON: Volunteers who lived through the ALS experience with a loved one 10 or 15 years ago, say they didn't have the services, information or programs available today. There was nothing like a PEG (percutaneous endoscopic gastrostomy or feeding tube) or noninvasive ventilation. We didn't have the prescription drug Rilutek®. I'm thankful for where we are and what we have to offer people now, but I also wonder what it will be like in 10 years. How many combination therapies will we have? How many technologies for breathing that we can't even imagine today? What sort of nutritional plan will we have that can really make a meaningful difference? Will we be able to help more people, who can no longer move their muscles or communicate effectively, to have hope and quality in their lives?

Improving the quality of



Edmond Asouline
(non-invasive ventilation)

Anne Walker (walker) and
friend Yvonne Overton

HOPE: Are those our challenges in patient care?

LYON: Yes. How do we help people make informed decisions based on what alternatives are available to them – the options they have about their care and how they live to make life as rich and as meaningful as possible. For example, many who choose long-term invasive ventilation have very rich, productive, meaningful lives for many years. ALS becomes a part of their life, but they continue their personal lives and even their careers. They enjoy their families, and do much of what they would have done without ALS.

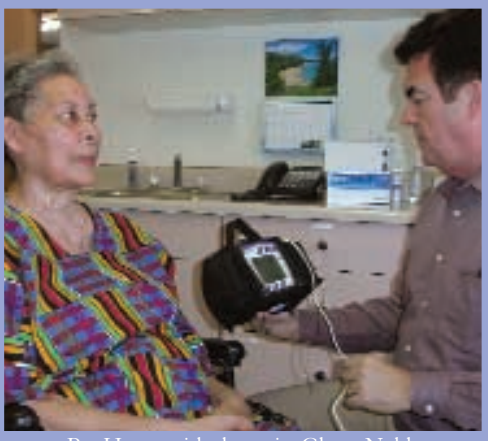
HOPE: Would you discuss some of your experiences with people with ALS and their families?

LYON: It's very common to hear that ALS affects only the nicest people. There was even an educational poster asking, "Why are people with ALS so nice?" They are some of the most

courageous people that I've ever met in terms of living and battling this disease; being willing, in many cases, to go public with their stories. I don't know that I've met anyone with ALS who hasn't wanted to help make it easier for someone else, whether or not there was anything in it for them. This could mean getting involved in research, writing a book, creating a video or in some way doing some-thing that would help others. I also see a lot of humor with patients and family members. In support groups and in other meetings, people explain that ALS creates many physical challenges. As a consequence, people with ALS tell a lot of funny stories about how they solved problems and got things done, sometimes in a non-traditional way. ALS is certainly a family disease, and one of the tragedies of the disease is that it affects everyone in the family, the extended family, employers, church members, neighbors and friends. ALS has an impact on the whole community. Statistically, for every person with ALS, it is estimated that at least 200 people have a relationship with that person and are also affected in some way. In addition, there are a lot of important psychological issues not only for the people with ALS, but for their families. Certainly anger, depression and anxiety are very common and understandable. It's not unusual for people to have a sense of denial of the disease and to look for other answers. That's really very normal and healthy. It can be an effective coping strategy, particularly early in the disease. We only begin to get concerned if this interferes with interventions or promotes other activities that may be harmful to the patient. We at The ALS Association try to help people regain control in their lives. Perhaps not in the same way they previously had control, but control over activities, control over as many functions as possible – albeit with assistive equipment or by doing things in different ways. Also, helping others to see them, and seeing themselves, as the same person on the inside that they've always been. To help them maintain a similar role in the family as father, mother, sister, brother, parent or child as they've had before, and to maintain personal dignity and personal sense of empowerment.

life for people with ALS

Neil Brourman
(invasive ventilation)



Pat Hayes with therapist Glenn Noble
(oxygen/CO_2 monitor)

HOPE: What makes an ALSA Center special for the ALS community?

LYON: Primarily, it is the philosophy of care and the caring expertise of the ALS clinicians. To become certified, a center must have a medical director who is a nationally known neuromuscular physician who regularly attends national meetings and keeps up with the newest research and treatment for ALS. Also, the medical director should be involved in research, presenting at national meetings and actively involved with their peers in improving care for people with ALS. In addition, they gather around them a team of allied healthcare professionals who have each developed an area of sub-specialty in ALS that includes not only knowledge about the disease, but experience in how to care for patients within their discipline, whether it's physical therapy or social work, with a whole set of interventions specific for people with ALS. Another remarkable thing about the ALSA Centers is that it is very much a family approach. The entire team, including medical and the clinical staff and the chapter representatives, embrace not only the patients but the family. They welcome family members into the clinic, and include them in all discussions and plans for care. ALSA Centers are the hub in the management of ALS, providing excellence in care and services in partnership with their local ALSA chapter.

HOPE: What message does ALSA give to a person who has just been diagnosed with ALS?

LYON: The patient has the control to make decisions. And, there are a number of decisions that will provide opportunities. The most important thing, from our perspective, is helping people get authoritative information that allows them to make informed decisions. ALSA provides a wealth of information and services that can help. This is really a time of hope. A lot can be done, and patients are not alone.

A note to the reader: The information contained in this article is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified healthcare providers must be consulted before beginning any treatment.

To read more of the interview with Mary Lyon, please visit http://www.alsa.org/patient/lyon.cfm

Biomarkers for an Accurate

"There is an urgent need to find a faster and more reliable diagnostic process that will enable earlier treatment and improve the likelihood that therapy will alter the course of ALS," said Lucie Bruijn, Ph.D., ALSA's science director and vice president.

The ALS Association is addressing this vitally important need through the funding of a groundbreaking new study using biomarkers – small molecules associated with ALS - found in cerebrospinal fluid and blood. The study, "Identification of Diagnostic Biomarkers and Therapeutic Targets for ALS," brings together leading researchers from academic institutions and biotechnology sectors in a collaborative project that utilizes cutting-edge technologies.

> "Biomarkers are absolutely key to a diagnosis."

Biomarkers can be genetic mutations (changes in the sequence of a gene), protein alterations or products from metabolic pathways. Biomarkers are a characteristic that is measured and evaluated as an indicator of normal biologic processes, pathogenic processes or pharmacologic responses to a therapeutic intervention.

Robert Bowser, Ph.D., University of Pittsburgh School of Medicine and Nnaja Okorafor, student researcher

Researchers believe that biomarkers for ALS are more likely to be detected in the cerebrospinal fluid that is contained in the central nervous system and bathes motor neurons in the spinal cord and brain. This fluid is in direct contact with cells that are dying in the ALS disease progression.

A preliminary study, conducted by Robert Bowser, Ph.D. at the University of Pittsburgh School of Medicine in 2003, found several small proteins in the cerebrospinal fluid of ALS patients that are not present in the same fluid from control patients and are potential diagnostic markers for ALS.

Dr. Bowser and his team employed RL (Rule Learner) algorithm analysis of the cerebrospinal fluid data to identify and generate rules to diagnose patient samples. "Using the RL algorithm, we have identified 10 biomarkers that diagnose ALS with 92% sensitivity and 86% accuracy from blinded test subjects," Dr. Bowser explained. "These putative biomarkers were most predictive for early stage disease."

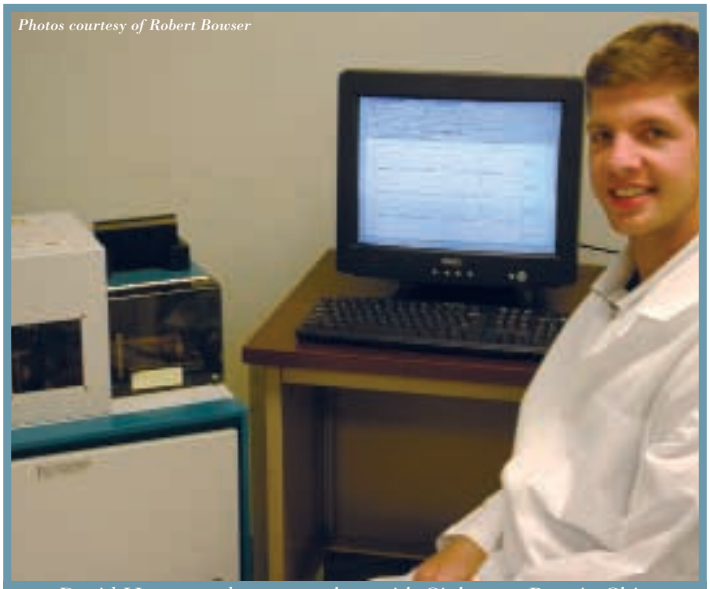
In the new ALSA-funded study, the Ciphergen Protein Chip mass spectrometry proteomic system will be used to confirm the initial findings in a larger sample pool of cerebrospinal fluid and blood taken from ALS patients and control patients. Samples obtained from Massachusetts General Hospital and the University of Pittsburgh will include a variety of other neurological disorders, including Alzheimer's disease. The diversity of control samples is absolutely critical in order to ensure that markers identified are specific to ALS.

This same set of samples gathered from Massachusetts General Hospital and the University of Pittsburgh will also be tested by Metabolon, Inc, where the company's metabolomics platform will search for signatures of ALS by accurately measuring the spectrum of biochemical changes and mapping these changes to metabolic pathways. Metabolon is a leader in the application of metabolomics, a powerful and new scientific approach for the discovery and development of drugs and the early diagnosis of disease states.

In pilot studies, Metabolon has already established metabolic profiles from the blood of ALS patients for comparison to profiles from control groups. Initial studies have identified markers

– Searching ALS Diagnosis

By Janet Young



Photos courtesy of Robert Bowser

David Henry, student researcher, with Ciphergen Protein Chip mass spectrometry proteomic system

that can be used to distinguish disease tissue from normal tissue. To extend these findings, Metabolon investigators are expanding the study to the larger sample set and will analyze the profiles in cerebrospinal fluid.

"We are looking for changes in proteins that occur in the cerebrospinal fluid of ALS patients near the time of symptom onset in an effort to identify potential diagnostic biomarkers that distinguish control subjects in our study," explained Dr. Bowser.

Dr. Bowser and his team are continuing to perform RL algorithm analysis with a larger number of test subjects in an effort to refine the biomarker panel. Researchers will also work to determine the protein identity of each biomarker, evaluate how the biomarker signature patterns change during disease progression, identify the biomarker pattern in SOD1 mice, and determine if biomarkers can be used to test drug effectiveness in clinical trials.

In addition to finding a reliable diagnostic process, this research may yield new methods to determine the progress of ALS by comparing the amounts of biomarkers at early and late stages. Also, this test may make it possible for researchers to measure the effectiveness of different drug treatments in clinical trials.

"ALSA has created a unique scientific collaboration that will greatly increase the speed by which we identify diagnostic biomarkers for ALS and gain new insight into the mechanisms of the disease," said Dr. Bowser. "We are very excited about the opportunities provided by this new collaborative research project."

"Biomarkers are absolutely key to a diagnosis if, in fact, you have a true biomarker. Our challenge is to do the best study possible to ensure the biomarkers we identify are true markers of the disease," Dr. Bruijn explained. "We do this through large sample numbers, a variety of techniques, and thorough validation of our findings."

Dr. Bowser is working in partnership with Merit Cudkowicz, M.D. and Robert Brown, Jr., M.D. from Massachusetts General Hospital, and Rima Kaddurah-Daouk, Ph.D. from Metabolon, Inc. in North Carolina.

"The promise of biomarkers is extremely exciting," Dr. Bruijn said. "It is our hope that this research will lead to earlier and more effective therapy for ALS patients."

To provide samples for this study, patients and physicians should contact Merit Cudkowicz, M.D. at 617-726-0563, Kristyn Newhall at 617-726-9122 or Robert Bowser, Ph.D. at 412-383-7819. Investigators are seeking to analyze samples from familial ALS, sporadic ALS, primary lateral sclerosis, pure lower motor neuron disease, and healthy control subjects.

This unique research was initiated by The ALS Association as part of the Lou Gehrig Challenge: Cure ALS Research Program. The Lou Gehrig Challenge is the most ambitious and promising privately funded research program ever undertaken aimed specifically at finding effective treatments and, ultimately, a cure for ALS. To learn more about The Lou Gehrig Challenge, contact The ALS Association toll-free at 866-CURE-ALS (866-287-3257) or send an e-mail to lgc-campaign@alsa-national.org.

Dean and Kathleen Rasmussen

Working in Partnership to Find a Cure for ALS

"When my father was diagnosed with ALS it was absolutely agonizing for our family," ALSA National Trustee Dean Rasmussen shared. "And, we were frustrated because there was nothing we could do to stop the progression of the disease."

Carl Rasmussen, Dean's father, lost his battle with ALS in 1989 at the age of 69, just nine short months after diagnosis. "My father was a very personable man with a great deal of passion for life and for helping people," Dean remembered. "He didn't like to ask for help himself, and it was very hard to see him brought to the point where he had to totally rely on the help of others just to survive each day."

Dean strongly believes that everything happens for a reason and, as he dealt with the grief of losing his father, he began to realize that he had to devote his time, his talents and his resources to the fight against ALS. "When my father passed away, I realized my mission in life was to help find a cure for this devastating disease," Dean said.

"When my father passed away, I realized my mission in life was to help find a cure for this devastating disease."

Dean is joined in his passion to find a cure for ALS by his wife of three years, Kathleen. "I never knew Carl," Kathleen said. "But through Dean, I've learned who Carl was and I've grown very committed to The ALS Association and to helping patients and families live with this disease."

Photo by Susan Bordelon

Kathleen and Dean Rasmussen

When Dean first began supporting The ALS Association, his primary focus was ALSA's premier ALS research enterprise.

Through the years, however, he has expanded his focus to include ALSA's advocacy efforts.

"I realized that through advocacy we could actually multiply the support for our research program by encouraging the support not only of individuals, but by gaining the backing of those in decision making roles within our government," Dean explained.

In 1993, Dean became an active member of The ALS Association's National Board of Trustees, and he currently serves on the Finance, Community Services, Research and Advocacy Committees.

Dean and Kathleen share a strong interest in ALSA's advocacy efforts and participated together in this year's National Advocacy Day, held in May in Washington, D.C. The event gathered nearly 700 ALSA advocates, including persons with ALS, families, and friends devoted to finding the answers to ALS.

"This year, the opening candlelight vigil on the steps of the Jefferson Memorial was incredibly beautiful," Dean said. "The vigil brought together patients, family members and others as we remembered the loved ones we have lost to ALS. Through National Advocacy Day, we develop a united voice to tell a powerful and compelling story."

Another highlight of National Advocacy Day for the Rasmussens was witnessing the incredible outpouring of support from elected officials. "When you're meeting with someone and explaining ALSA's mission, and you see the light turn on as they realize how important and how urgent it is to find treatments and a cure, it's very powerful. You know you've made a difference," added Kathleen.

ALSA's advocacy efforts have resulted in the passage of a monumental presumptive disability ruling for persons with ALS by the Social Security Administration, the historic passage of the 24-month Medicare waiver for ALS patients, increased funding for National Institutes of Health (NIH) research and two consecutive years of specialized funding for ALS by the Department of Defense under the Peer-Reviewed Medical Research Program.

"ALSA would not have an Advocacy Department were it not for the vision and financial contributions of Dean Rasmussen," said Steve Gibson, ALSA's vice president, Government Relations and Public Affairs. "He realized that through advocacy we could share the needs of people with ALS on a national level and encourage significant support from the government into ALS research and quality of life issues."

"Through advocacy we could actually multiply the support for our research program."

Dean and Kathleen hope to see ALSA's advocacy efforts continue to grow in coming years. Dean is actively involved in developing a five-year plan focused on building stronger relationships with the

Candlelight vigil in Washington, D.C., May 2004

NIH, the Department of Defense, and other government funding agencies that can make an impact in the fight against ALS.

"Our work in Washington, D.C., is so vitally important for The ALS Association," Dean said. "We need to raise awareness on a national level to effectively support ALSA's mission."

In addition to their commitment to the national organization, Dean and Kathleen are strong supporters of The ALS Association's Greater Los Angeles Chapter, where Kathleen is vice president of the chapter.

"It is through ALSA's chapter network that we can meet the needs of patients and families across the country, whether by loaning medical equipment and communications devices, or providing support groups and other emotional support," Kathleen explained. "It is our hope that we can expand the number of chapters so we can reach out to every ALS patient in the country."

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Among Kathleen's goals with The Greater Los Angeles Chapter are helping to establish a Center of Excellence in Los Angeles, ensuring that the chapter remains able to provide the highest quality of service to patients and families, and augmenting leadership in an effort to grow the chapter. Dean added that on the chapter level, he would like to see ALSA's signature event, the Walk to D'Feet ALS®, grow in an effort to raise awareness in communities across the country. "The Walks are an important grassroots effort," Dean said.

According to Fred Fisher, executive director of The Greater Los Angeles Chapter, "Dean and Kathleen care deeply about the chapter and the patients in our service area. Their philanthropic spirit, combined with their vision of a caring community in service to our PALS, has supported the chapter's effort to expand services to ALS patients. In addition, Dean and Kathleen have helped raise the bar in terms of the role of Board members, and they have strengthened the fundraising capacity of the chapter, all in an effort to better serve the growing number of ALS patients and families in our community."

Dean is Chairman and CEO of C.A. Rasmussen, Inc., a general engineering contracting firm based in Simi Valley, Calif. and founded by Carl Rasmussen in 1964. Dean joined the firm in 1968 following graduation from Arizona State University and had the opportunity to work alongside his father for several years. "I feel fortunate to have worked with him and to have been in business with him," Dean shared.

Following graduation from Smith College in Massachusetts, Kathleen spent many years working in the areas of public relations and development for schools and colleges. She now applies her strong marketing and fundraising skills to her work with The Greater Los Angeles Chapter.

Between them, the Rasmussens have four children, Jeremy, Erin, Eric and Andy. Dean and Kathleen enjoy traveling and collecting art and antiques. Also, they are staunch supporters of education, providing support to Harvey Mudd College, Viewpoint School and a Boys and Girls Club in Southern California.

However, The ALS Association continues to be a major focus in their lives. "We are partners in the fight against ALS," Kathleen added. "I support Dean in his advocacy work, and he supports me in my role with The Greater Los Angeles Chapter. We see ourselves as a team, and we are doing this together."

"After family loses a loved one to ALS, it can be difficult to continue to work in support of finding a cure," Dean shared. "I had to confront the devastation that is ALS and accept the emotional challenges that come with supporting The ALS Association to help eradicate this disease."

"The compassion and dedication of Dean and Kathleen Rasmussen means a great deal to everyone at The ALS Association," Gary Leo, ALSA's President said. "They give of themselves not only through tremendous financial support, but they also both give so generously of their time and their incredible talents. With the Rasmussens as our partners in the fight against ALS, I am confident we will achieve our goals of finding effective treatments and a cure for this devastating disease." – JY

(L to R) Speaker of the House Dennis Hastert (R-14th Ill.), actor Alan Rosenberg, Dean & Kathleen Rasmussen on the Speaker's Balcony at the U.S. Capitol

LIVING WITH ALS
THE IMPORTANCE OF BEING ME

By Sandy Stuban

Sandy Stuban

Sandy Stuban, 47, was a Lt. Col. in the Army Nurse Corps when she was diagnosed with ALS in 1995. She lives with her husband Steve and their nine year old son Nick in Fairfax, Virginia.

After living with ALS for nine years, I have recognized the importance of being me. We all have our own personality and values that give us satisfaction and meaning in our lives. When a diagnosis of ALS is made and you begin to lose physical abilities, it's easy to also lose sight of who you are. You fall into a downward spiral of being complacent, unmotivated, and unexcited about life. The very things that made you happy and content before ALS are now conspicuously absent. Why? You must recover your personality and values to recover the satisfaction and meaning in your life as you face the challenges of ALS. You must continue to be you. How do you do that?

> **"You may wonder how a quadriplegic on a ventilator can possibly feel any sense of independence."**

I want to share with you some of my personality traits and values that I lost for a while then regained to find that life truly can be satisfying and enjoyable despite advanced ALS. I found that sometimes you have to be creative and think outside the box.

> **"My greatest source of independence is through my computer."**

The need to be independent. I was fiercely independent and absolutely devastated to lose my independence as I lost physical abilities to ALS. I had to regain this to survive ALS. You may wonder how a quadriplegic on a ventilator can possibly feel any sense of independence. First, I had to accept those things I absolutely needed help with, those things I had no power to change. Then, I identified those things I could change. My greatest source of independence is through my computer; "EZ Keys for Windows" allows me to operate all computer functions. Because I have no movement below my neck, I use an infrared motion sensor positioned next to my cheek to operate my computer. Once set up, I am completely independent. I pay the bills, register my son for summer camp, do the payroll for my hired caregivers, order books from the county library, shop for birthdays and Christmas, do research, email, to mention just a few things. I can't emphasize enough how a computer can be your liberator.

The need to help others. As a trained nurse, my innate desire is to help others and make a difference in their lives. Having to receive care instead of giving it made me feel frustrated and unfulfilled. To continue to function in my role as a nurse, I became involved in an ALS chatroom and communicated with others living with ALS. In addition, I have written several articles for professional nursing journals to help educate my fellow nurses. This is very satisfying, and I plan to continue to help and make a difference where I can.

> **"I am a wife and mother to the two wonderful men in my life."**

The need to be involved. I had always been a very active person before ALS and could easily run circles around most people. When I began losing physical abilities, I couldn't imagine how I could continue to live in the style I was accustomed to. The reality is that you can't live in the past. Living with ALS requires adapting to a new lifestyle. But, I needed to be active and involved to be happy, so I participate in ALSA's annual Walk to D'Feet ALS®, which is held in major cities across the nation. Funding research and increasing awareness are both important to me. I am a board member of a local nursing organization and a committee member at a local university to raise money for nursing scholarships. I manage a monthly book club in my home. Plus, I am a wife and mother to the two wonderful men in my life.

I have figured out how to be me and be satisfied with my circumstances. If you are newly diagnosed or are in the transition of losing abilities, don't lose sight of who you are. You must actively pursue new avenues to express your personality to be content. Caregivers should be active participants in suggesting out-of-the-box ideas to help your loved one find appropriate and satisfying outlets to express themselves. I believe the key to living with ALS is by being me. And by you being you.

Sandy with son Nick

LEGACY OF

HOPE

William Larue

William's Story *By Juan Ros*

Tribute to a Real Fighter

Bill Larue was known as the "laughing gladiator." An amateur boxing champion, he was well-known to many San Franciscans in the 1920s and early 1930s for his athletic prowess and for his considerable charitable work with local organizations.

Bill's son, William, was a teenager when his father was diagnosed with ALS. "I really didn't know my father for a critical period of time when I was growing up," William recalls. "I was deprived of his companionship while he spent a lot of time in hospitals."

Just 17 years old when his father passed away, William remembers him fondly. "He never lost his good spirits and his humor. He was always doing something for others."

William, now retired from the financial services industry, says it was always in the back of his mind to do something significant to help in the fight against ALS. With no children of his own, he was also concerned about the best way to distribute his estate.

William recently searched online for an organization that would accomplish his philanthropic objective. "I was looking for someone dedicated to eradicating this disease. From 10 possible organizations, I selected The ALS Association (ALSA) as the best qualified to do the job." He says he was impressed by ALSA's research program and low administration expenses.

Needing to revise his estate plans in light of recent changes in tax law, William decided to include The ALS Association in his living trust, along with two other charities close to his heart. William is remembering family first with specific bequests, and then splitting the remainder of his estate equally among his three chosen charities, including ALSA. This arrangement allows William to avoid estate taxes and, more importantly for him, provide meaningful support for those charities he cares for.

William's legacy to ALSA is a tribute to his father. "I can see the terrible toll this disease takes on families, particularly the spouse and children," he says. "I obviously hope you'll find some cure for ALS soon. New avenues of research, particularly stem cells and genome research, make me very hopeful."

DESIGNS FOR GIVING

You can make a difference by leaving a legacy of hope through a gift in your will or trust to The ALS Association. Your gift can benefit the National Office, your local ALSA Chapter, or both. To receive more information, please return the enclosed coupon, or call Juan Ros toll-free at the National Office at 888-949-2577, extension 212. Your inquiry will be strictly confidential.

❑ I/We have remembered The ALS Association in my/our estate plan.

❑ I/We would consider including The ALS Association in my/our estate plan.

❑ I/We would like to receive free information about how to leave a "legacy of hope" to The ALS Association. Please send the following booklet(s):

- ❑ Giving Through Your Will
- ❑ Giving Through Living Trusts
- ❑ Your Legacy of Hope…
  The Lou Gehrig Legacy Society of The ALS Association

❑ Please contact me to discuss my "legacy of hope."

Name

Street

City State Zip

Please call me at ( )

Mail completed form to:

The ALS Association
27001 Agoura Road, Suite 150
Calabasas Hills, California, 91301-5104
or Fax to: 818-880-9006
Attention: Juan Ros

GIVING STOCK?

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Wachovia Securities
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For more information, or to notify ALSA of a gift of stock, please contact Juan Ros, toll free, at 888-949-2577, extension 212, or via e-mail at juan@alsa-national.org.

The ALS Association and Minor League Baseball Team Up to Fight Lou Gehrig's Disease

ALSA is an official charity partner of Minor League Baseball. Local ball clubs and ALSA chapters are working together to increase awareness about the fight against ALS and to raise funds to support ALSA's international research effort and world-class patient services activities.

In cities across the nation, Minor League Baseball and ALSA participate in joint activities such as the World's Largest Jersey signing, Lou Gehrig Night-at-the-Park and club-sponsored Walk to D'Feet ALS® teams, in addition to such fundraising events as raffles, celebrity-waiter dinners, golf tournaments, and player autograph auctions.

The ALS Association is proud of its partnership with Minor League Baseball and encourages everyone to go out to the park and support the ball club in your area. Your involvement will help find a cure and improve the lives of people living with ALS.

walk to d'feet ALS®

STEP UP TO THE CHALLENGE!

THE ALS ASSOCIATION'S WALK TO D'FEET ALS®

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