ALS Adopted As Philanthropy

BY PENNY GILL

At the February meeting of the General Officers of Phi Delta Theta the General Council approved the National ALS Foundation as its primary philanthropy.

ALS stands for Amyotrophic Lateral Sclerosis but it is more commonly known as the Lou Gehrigs's Disease. According to Brian Dunn (Cornell '77), the Community Service Day chairman for the fraternity, "the designation of the National ALS Foundation as a primary philanthropy comes as a result of our decision to try and focus the collective efforts of the fraternity in an area where we can have a true and lasting impact."

"At the same time we will continue to encourage and promote the individual efforts of the chapters to assist their local community. Many chapters have events that are rich in tradition and in no way should this new program detract from those traditions."

Henry Louis Gehrig was not only one of the all time greats of baseball history, he was a brother in the Bond of Phi Delta Theta. The "pride of the Yankees" signed the Bond at New York Delta (Columbia University) on April 18, 1922; near the end of his junior year. Despite the fact that Lou was a modest and shy young man he was, even then, somewhat of a celebrity having starred on the football and baseball teams.

One of the fraternity brothers who helped to initiate Gehrig was classmate Joseph A. Lillard (Columbia '23), now living in Hastings-on-Hudson, New York.

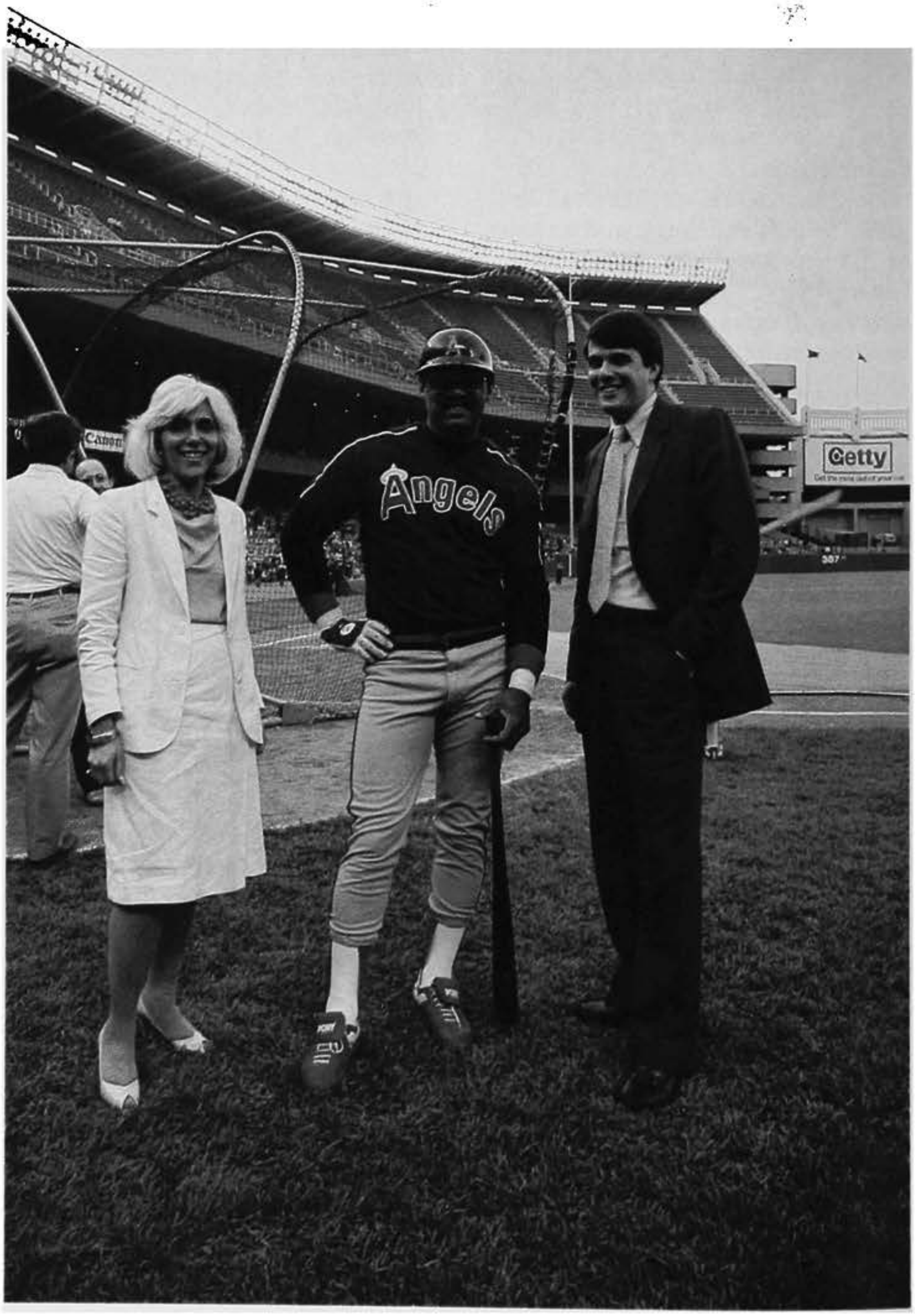
"Usually when Lou was through with his activities on campus he went home, but I do remember him coming by the fraternity house for dinner from time to time," he says. "He was an awfully nice fellow; but I think his main interests were his mother, classes and the ball game—perhaps in that order!"

Graham Gardner (Columbia '23) who now lives in Southbury, Conn., recalls: "Above all, he had a reputation for being an excellent ballplayer. In fact, that's how he was presented to us for initiation, that such a good sportsman would enhance the image of the fraternity."

Their memories of Lou Gehrig, student and fraternity brother, evolve easily into the public memory of Lou Gehrig, the "Iron Horse" and Yankee first baseman. And from his tenure as a Phi Delt Lou Gehrig will always be considered one of the chapter's most illustrious brothers.

From the time he joined the

ALS CHAIRMAN: Reggie Jackson, outfielder for the California Angels and national chairman for ALS, is flanked by Penny Gill of the National ALS Foundation and Brian Dunn, Phi Delta Theta Community Service Day chairman. Photo by Chad Weckler.



Yankees in 1923, to the day he gave his farewell speech in 1939, Gehrig's talent and reputation as a ballplayer were outshone only by his humility and courage. His untimely death at the age of 39 was mourned by the entire nation, and it is a tragic tribute that the disease that took his life, Amyotrophic Lateral Sclerosis (ALS), has come to be known as "Lou Gehrig's disease"!

It was particularly unfitting that such a strong and physically powerful man should be afflicted by a disease that gradually destroys all muscle function, ending eventually in total paralysis while leaving the mind unaffected. After all, this was a ball player who did not miss one game in 14 consecutive years; who was named four times the Most Valuable Player in the American League; whose incredible streak of 2,130 games remains a record unbroken to this day.

The admirable qualities of humility and courage that were so evident in Lou Gehrig were perhaps never displayed more clearly than in his farewell speech to a crowd of thousands, packed into Yankee Stadium on July 4, 1939. Gehrig had less than two years to live when he said:

"Fans, for the past two weeks you have been reading about what a bad break I got. Yet today, I consider myself the luckiest man on earth. I have been in ballparks for 17 years, have never received anything but kindness and encouragement from you fans...

"When you have a wife who has been a tower of strength, and shown more courage than you dreamed existed—that's the finest I know. So I close in saying that I might have had a tough break, but I have an awful lot to live for."

Even after his official farewell, Gehrig stayed connected to baseball by becoming a member of the Parole Commission. Said Pete Sheehy, a Yankee clubhouse man who arrived at Yankee Stadium in 1927 and who became one of Lou's closest friends:

"Lou always had to be in a position where he could do something for somebody."

That spirit could be said to form the basis for Phi Delta Theta's new commitment to not only honor its brother, Lou Gehrig, but to "do something for somebody" by adopting the National ALS Foundation as the fraternity's primary charity. Through our efforts in concert with the Foundation's activities, we will strive to help put an end to "Lou's" disease.

This is not the first time that Phi Delta Theta has honored the baseball great. A special Lou Gehrig award was created in 1955, to be awarded annually to a young major leaguer who best exemplified the sportsmanship qualities of the great Yankee first baseman. A permanent plaque, inscribed with the names of the winners, is located in the international offices of the fraternity.

In a different vein, two Phi Delts indirectly honored Gehrig in developing a special communications device that enables nonverbal patients, such as those in the latter stages of ALS, to communicate with their eyes. The ETRAN Communicator (see Scroll, Fall 1982) was invented by Jack Eichler, (Case '41), and further developed and produced by Warren Rupp, (Case '42) through the Fran and Warren Rupp Foundation. The device has now been donated by Rupp for distribution by the National ALS Foundation.

Established in 1971, the National ALS Foundation was formed to organize efforts in the fight against ALS. Among its goals is the increasing of public awareness of the disease, which most people think of as rare. Actually, the incidence of ALS is about four times as great as Muscular Dystrophy, and equal to that of Multiple Sclerosis. In other terms, it afflicts about 2 out of every 125,000 people, with no regard to geographies, race or ethnic background.

ALS most frequently strikes between the ages of 40 and 60, although older and younger victims (such as Lou Gehrig) are reported. It is a progressive disease, characterized by degeneration of nerve cells and pathways in the brain and spinal cord which leads to eventual total paralysis of the muscles, including those that control vital functions such as speech, swallowing and respiration. At the same time, the mind is not affected, which led one patient to describe the disease as "having a ringside seat at one's own demise."

The cause and cure for ALS are currently unknown; yet through the efforts of organizations like the National ALS Foundation, funds for research have grown from under $1 million annually before 1971, to about $20 million annually today. This area of stimulating and supporting research is the primary goal of the Foundation, which has also established a registry and brain-bank for scientists active in the study of ALS.

In order to generate more funds to that end, the Foundation also has a broad-range program to increase awareness of the disease on all fronts. Former Yankee and now California Angel Reggie Jackson is at the forefront of the campaign as the Foundation's National Chairman. His endorsement of the organization's activities, as well as his appearance in a series of public service announcements keep the baseball connection to the disease strong, while generating public awareness through his own renown.

Another important aspect of the National ALS Foundation's work, and one which Phi Delta Theta has already entered with its Community Service Day last spring, is in patient services. The Foundation maintains a corps of volunteers to offer assistance to ALS patients and their families, whether by merely keeping a house-ridden patient company, or by performing household chores, such as mowing the lawn or shoveling snow. This "outreach program" is especially important in helping morale since ALS patients tend to feel an extreme sense of isolation, and was one of the activities chosen by some Phi Delts for their community service last May.

The Patient Services program of the Foundation is carried to the professional level in the way of three ALS Clinics, all established under the organization's sponsorship. Currently located in New York, Chicago and Miami, the growing roster of Clinics are the first of their kind devoted specifically to the care and counseling of ALS patients and families. They offer an interdisciplinary team approach to the disease, with staff that includes a wide range of specialists from neurologists to occupational therapists, psychologists, speech pathologists and social workers.

On a local level, and here again is a potential opportunity for tie-in by Phi Delta chapters, the National ALS Foundation has developed a network of ALS Chapters for various cities and regions. This network is still growing, staffed primarily by volunteers who have experienced or who are experiencing ALS in their lives. They support the national group in all its various programs of fundraising, public awareness and patient services.

The fight against Mayotrophic Lateral Scolerosis is currently supported through two national foundations: The National ALS Foundation (NALS) and the ALS Society of America (ALSSOA). Those organizations seek to increase public awareness of the disease, support research, and aid those afflicted with this disease. While the fraternity has adopted NALS as a primary philantrophy, this action does not prevent support of ALSSOA and its activities by chapters of the fraternity.

There is a lot of work that can and needs to be done to fight this disease that has taken too many lives, including that of Lou Gehrig. Just as he was never satisfied that he was doing enough—his former teammate and now California Angels coach Jimmy Reese said:

"He always did a little more than he was supposed to do"—here is the chance for Phi Delta Theta to do a little more, so that someday perhaps no one else will have to die as Lou Gehrig did. ■

Kansas City Phi Spearheads ALS Drive

BY TOM LEATHERS

Sue Worthington arises shortly after 7:30 a.m. each day at her home in Prairie Village, Kansas, a quality sub-division that adjoins Kansas City, Mo. A leisurely hour to be sure, and in keeping with the leisurely appearance of the neighborhood in which she lives with her husband, Keith (Missouri '53), a former executive of an exclusive men's clothing store.

So you would no doubt expect Sue Worthington to follow a day deserving of her surroundings—household chores, take the kids someplace, volunteer work, maybe tennis and lunch with friends at the club, a nice dinner at the home or out with her husband.

But Sue Worthington's day is much different—different from anyone else you know. First you should know that she didn't go to bed til after midnight. And when she did, she didn't sleep soundly—keeping one ear open for any trouble happening to the man in the next room. That's because her husband has Amyotrophic Lateral Sclerosis (ALS) or more commonly known as Lou Gehrig's disease. And she personally must care for him like few have to care—for all but those few hours she might catch a little sleep. The disease affects both the nerves leading from the brain to the spinal cord and those to the muscles. And requires constant care—like you can't imagine. In up to 20 per cent of all cases, irrespective of treatment, ALS plateaus for extended periods of time and often arrests permanently. But fifty per cent of the patients with ALS die in approximately three years—with 20 per cent surviving beyond 10 years. Patients, when they do die from ALS do not die from the disease directly but from treatable symptoms.

Keith's had it for nearly 11 years. The last 42 months he's spent connected to a respirator. Without it, he would deteriorate within a short time. With it, he lives—lives to tell the story of ALS. But even more important, to wage a valiant effort—one that has been helped by a group from Rotary Club 13 in Kansas City—one of Rotary's largest and most active clubs. The club, as well as others in the district, have joined together to help raise money, sponsor projects. They have become a catalyst for the work of fellow Rotarian Keith.

There is a national president—Eames Bishop of Los Angeles. He got active in the ALS campaign after his wife came down with the disease. He criss-crosses the country trying to alert the public and raise funds. But he points to Keith as no doubt the one person who has given the most.

"He's truly a one-man gang," Eames says. And he's right. Through Keith's efforts a major research center for ALS opened this year only a few miles from his home—as a part of the University of Kansas Medical Center. The research facility can use the many support services of the many departments at the famed medical center.

Officials there admit that one man, Keith Worthington, inspired it all. Those that meet him come away in disbelief. They can't believe that someone who has trouble breathing, can hardly move a muscle and can't speak, can do so much.

The truth is he can do it because of his courage and because Sue is willing and somehow able to give the enormous amount of care and the time it takes to get an ALS patient through the day and the night. A torturous routine that most people would find difficult to follow for one day—or even one hour. But the Worthingtons go through it seven days a week—in an amazing display of courage and tenacity.

For instance, every two hours or so, Keith needs to be turned and suctioned. They must take a "catheter" and go into his lungs. But it takes much more. Countless tasks to keep him alive on a respirator.

Many ALS patients choose not to do it. The device, while a possible livesaver in some ways, places an enormous burden on the patient and those who care for him. It becomes necessary to hook him up and unhook him, monitor the unit, plus other continual care that almost isn't physically possible in a hospital, much less in a home setting.

But Keith and Sue decided to try it. For two reasons:

1. Keith earlier had met a man named Robert Dicus, an ALS patient in California who had enormous mental and physical determination. Dicus was on a respirator and was obviously leading a productive life.

2. By prolonging his life, Keith felt he would be able to help other patients—and the time to raise funds to help find a cure for the disease.

And that he has done. He has established an office in Prairie Village. And each afternoon from 2 to 5 p.m., he and Sue are driven to the ALS local headquarters he has established there. The afternoon then is spent sending out mailings, writing letters of advice and encouragement and talking on the phone to other patients (even though it is not only difficult for him to talk, but to be heard). And recently planning a fund-raising drive to provide money for an ALS research center that opened at K.U. Medical Center.

It sounds simple—going to the office to work, making phone calls, etc. Yet each step becomes a laborious project that would strain and perhaps eventually break even the strongest.

But Keith—and Sue—do it, and a lot of other things to survive and serve.

She's very grateful for those that help. But she worries about other patients that don't have friends and volunteers. Without them, survival for very long could be impossible.

When Keith's illness was diagnosed, he was a member of the downtown Dallas Rotary Club. About one year later, he returned to Kansas City and became active in Rotary Club 13. Since his illness, Rotary Club 13 has held two special "Keith Worthington Days" in his honor, with the speaker, H. Eames Bishop, president of ALSSOA. In 1979, Keith was named Rotarian of the year.

In 1981 Keith opened a branch office of the ALS Society in Kansas City. His major project was to establish an ALS Research Center at the University of Kansas Medical Center. With the total support of Eames Bishop and ALSSOA the Research Center became a reality in February of 1982. Thus far, $600,000 in ALS research has been approved. Rotary Club 13 has a goal of raising $200,000. Two long time members, Joe Gilbert and John Thornberry, are co-chairmen of this effort. Thus far, more than 60 Rotarians have volunteered to raise $1,000 a piece. In addition, five other Rotary Clubs in the area have appointed fund drive chairmen to help achieve the goal.

Sue is hoping for a cure for the disease, of course. But in the meantime, she's hoping that somehow a network of helpers will be found to help the others with ALS.

"Many patients have to stay in bed all day because no one is there to lift them out," she said. "And no one can take the hours needed to feed them. Often they die from something resulting from poor nutrition."

She paused and looked at Keith—and he smiled that infectious smile.

"We really have a lot to be thankful for," she said confidently. "We have super kids, so many friends—and 30 years of a perfect marriage." ■

WORTHINGTON: Keith R. Worthington receives the 1981 Kansas City Phi of the Year Award from Dean Graves 1980 recipient, while John W. Balland III, Brad Simpson, a nephew, and Kevin & Kirk Worthington, sons, watch.