

# VISION

## FEATURES

New Gene Discovery	1&2
Baseball Knocking out ALS	1&8
A Healing Journey	2
Cure ALS Campaign	3
Cassandra's Gift	4
Jane H. Gilbert Appointed	4
Mayo Clinic Honor Roll	5
Prognosis Delivers Roadmap to Cure	5
DynaVox Technology	6
Iraq Troops Fight ALS	6
Charitable Gift Annuities	7

## New Gene Discovery Continued from page 1

cases of ALS. Inherited cases together account for about 10% of all ALS. Scientists will use the new gene discovery to create cell and animal models, to examine in detail how the mutation operates and how it causes ALS.

Normally, the FUS gene carries out multiple functions within the motor neuron (motor neurons are the type of nerve cell affected in ALS). It is not yet known how mutations in the gene cause the disease, and this will be a major focus of future research. Importantly, the FUS gene is involved in some of the same processes as the other recently discovered ALS gene, called TDP-43.

“The fact that these two genes help perform the same function suggests that problems in this function may be critical in the development of ALS,” Dr. Bruijn said. “More research into exactly how these two genes work could ultimately lead to new treatments that are effective in slowing or stopping

the progression of ALS and extending the lives of people with the disease.”

The gene was discovered by an international team, including ALS Association-funded researchers Caroline Vance, Ph.D., and Christopher Shaw, M.D., of King's College in London, as well as Tom Kwiatkowski, M.D., Ph.D., at Massachusetts General Hospital, and Robert Brown, M.D., of the University of Massachusetts School of Medicine. The results were reported in the February 27 issue of the prestigious journal *Science*.

The project was supported by a consortium of leading ALS researchers from around the world, formed as part of The Association's Gene Identification Project. Their success reflects an unprecedented effort to accelerate the search for genetic mutations linked to all forms of ALS. Dr. Brown noted, “The ALS Association has been an all-important partner in this search. This discovery should lead to new cell and animal models of ALS, which will accelerate drug development.”

## A Healing Journey

by Katie Sweeney



Mariah Fenton Gladis with sons Luke and Cole.

Ron Gladis

In the summer of 1981, Mariah Fenton had everything to live for. Just 33, she was athletic and

active, had her own psychotherapy practice and was dating a wonderful man, Ron Gladis. The last thing she was expecting was an ALS diagnosis. Even worse, doctors at the time gave her only a 10 percent chance of living two years.

“It was terrifying and shocking,” she recalls. “As far as I knew, I was healthy. Luckily, Ron was very supportive and adamantly optimistic.”

In fact, three months later, the two were married, and Mariah soon became pregnant with their first child, Luke. Later, she gave birth to a second son, Cole. Today, 27 years after her diagnosis, both sons are grown—and Mariah Fenton Gladis has more than proved those first doctors wrong.

She continues to see a full caseload of clients at the Pennsylvania Gestalt Center she founded in 1976, has her own foundation, has received numerous professional awards and recently wrote and published a book, *Tales of a Wounded Healer: Creating Exact Moments of Healing*.

One way she's coped with the constant challenges of ALS is by focusing on helping others. In her work, she found a new sense of urgency to empower her patients to change and move beyond the pain in their lives. While writing *Tales of a Wounded Healer*, she gradually became more courageous about revealing deeper parts of herself in the book. She's now planning to write a second book.

“I love what I do, and it gives meaning to my life,” she says. “It also keeps me constantly focused on healing, so I'm in that healing energy hour after hour, day after day.” Her advice to others battling ALS? Maximize

your overall health; love and forgive everyone especially yourself; turn your anger into determination; and make peace with the possibility of death—while doing everything possible to stay alive and vital. And most importantly, reach toward people and things that offer hope.

Mariah's beacon of hope has been her husband, Ron, who spends much of his time caring for Mariah.

“It used to be hard for me to hear Mariah say she is a better person because of ALS,” Ron said. “But I understand it now. We manage grace, hope and gratitude because that's the learning that comes out of it.”

Your support helps The ALS Association provide services to people with ALS and their families and supports The Association's global research effort to find treatments and a cure for Lou Gehrig's Disease.