

Turning shock into action

► Plainville couple leads fight to find cure for lethal disease affecting son, 4

BY LAUREN CARTER
SUN CHRONICLE STAFF

PLAINVILLE — In many ways, Linda and Scott Hastings are fighting a race against time.

Their 4-year-old son, Ryan, is afflicted with Duchenne Muscular Dystrophy, a degenerative muscle disease with no known cure.

The nature of DMD is ominous and unrelenting, beginning with generalized weakness and leaving most children wheelchair-bound by age 10.

Most of those afflicted die before their 20th birthday, suffering a slow and painful deterioration of the voluntary muscles of the body, and eventually those around the heart and lungs.

The Muscular Dystrophy Association said that survival beyond the early 30s is rare.

Though the disease, which affects primarily boys — about one out of every 3,500 people worldwide — is usually carried through the mother, Ryan fell into a minority class of cases which result from spontaneous mutation.

Ryan's diagnosis actually came "by mistake" at age 2, when a visit to the doctor for stomach problems required blood tests, which revealed unusually high muscle enzyme counts.

The official diagnosis from Children's Hospital in Boston left the family stunned.



MIKE GEORGE / THE SUN CHRONICLE

Pulling together

Ryan Hastings, 4, left, is pictured with father Scott, sister Kaitlyn, 7, and mother Linda. Ryan has Duchenne Muscular Dystrophy, a muscle disease with no known cure.

"Of course it was absolutely, positively the most shocking thing in the entire world, because he had no symptoms to begin with," Linda Hastings said. "We were really in disbelief this could be his diagnosis."

But disbelief quickly transformed to resolve once the Hastings realized that, without a cure, Ryan's fate was as good as sealed.

In 2003, the family formed the Ryan's Hope Foundation, a nonprof-

it organization dedicated to raising money for DMD research, and ultimately, the Hastings hope, finding a cure for the lethal disorder.

Over the past few years the foundation has hosted golf tournaments, dinner and comedy nights, kids' nights and a number of other events to support DMD research initiatives, most recently raising \$26,000 at a dinner and comedy night in Boston.

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► HOPE: Kids' Night Out one of many events raising money aiding DMD fight

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Tonight, the family will hold a Kids' Night Out at Panera Bread in Plainville — already a partner with the foundation through its Operation Dough-Nation program — with 10 percent of the proceeds to benefit Ryan's Hope.

"War needs to be waged on this disease," Linda Hastings said. "Twenty years ago if a child was diagnosed with cancer it was a death sentence; now there's an 80 percent cure rate. I just think if there's enough awareness raised and we move research ahead, something can be done."

Thus far, research efforts have been relatively unproductive. The gene responsible for the disease was isolated in 1986, but since then no significant strides have been made.

The Hastings have recently started Ryan on steroids — called his "strong pills" — one of DMD's few known treatments, and still not fully endorsed by the medical com-

At a glance

WHAT: Kids' Night Out, with 10 percent of proceeds to benefit the Ryan's Hope Foundation to find a cure for Duchenne Muscular Dystrophy

WHERE: Panera Bread at Plainville Crossing, intersection of Routes 1 and 152, Plainville

WHEN: 5 to 8 tonight.

INFO: Magic Tricks, Balloon Art, Face Painting, Prize Drawing, Caricatures, and a special appearance by Scooby Doo

CONTACT: 508-699-3888 or www.HopeForRyan.com

munity because of side effects, though the Hastings say they've seen significant improvements.

"It's kind of narrowed the gap between what he can do and what his siblings and peers can do," Linda Hastings said,

▼
'War needs to be waged on this disease.'

Linda Hastings,
Ryan's mother

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referring to Ryan's two siblings — Kaitlyn, 7, and Hunter, 18 months.

Nightly stretches, therapeutic horseback riding and physical therapy at preschool twice a week have also helped, and based on doctor's checkups that involve timed physical tests, Ryan is doing better than average.

Still, the family knows that without a cure for DMD, it's only a matter of time.

"We are really in a race against the clock," Linda Hastings said. "He is doing really well right now, but we know that the muscles are dying a little bit every day."