Matt Eddy’s Journey of a Million Smiles

It may be a while before Matt Eddy knows if Guinness World Records certifies his “Journey of a Million Smiles” from coast to coast. But he knows for sure that between June 5 and October 9, 2010, he successfully traveled some 3,400 miles from Lynn, Massachusetts, to Long Beach, California, in his power wheelchair while using a ventilator to breathe.

Diagnosed at age 4 with Duchenne muscular dystrophy, a severe recessive neuromuscular disease characterized by progressive muscle degeneration, Matt has used a wheelchair since he was 10. He has used a ventilator since having a tracheotomy at age 20. Now 33 years old, he operates his wheelchair with the only two fingers he can still move.

Accompanied by his respiratory therapist, Ron Steenbruggen, Ron’s daughter Dani and a friend, plus two Boston terriers, Matt set a goal of raising $1 each from a million people for Matt’s Place Inc. (www.officialmattsplace.org) during his trek across America. Contributors could sign the RV that housed Matt and crew at night. To gain more visibility for the effort, Matt received approval from Guinness World Records to register a new category: Trans-USA by Wheelchair.

Matt’s Place was created 10 years ago when Matt was dismissed from a rehabilitation facility and needed customized, accessible housing. Ron was an RT at the facility and, recognizing Matt’s dilemma, bought and renovated a house adapted to Matt’s needs. Since then, Matt’s Place has incorporated as a nonprofit organization whose mission is to build accessible housing, provide community awareness and education, offer personal care staff assistance and help with the transition from health care facilities to home.

“The cost of institutionalization is extraordinary,” said Ron. “The fact is that people are happier and stay healthier in their own homes, but they face financial and daily living challenges in finding appropriate housing. Instead of focusing on research and cures, the mission of Matt’s Place is to improve the lives of individuals with severe disabilities.”

Matt and Ron had made the trip two years earlier by wheelchair and bicycle, to raise awareness for people with disabilities who want to live independently and to fulfill Matt’s dream of seeing the country. They camped in a tent at night, but found that it took
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several hours each day to set up the
tent and Matt's equipment – suction
machine, ventilator, humidifier and
battery charger. For this trip, the RV
would house the equipment and pro-
vide a more comfortable environment
for sleeping.

But during the day, Matt and Ron still
had to brave the elements ranging
from below freezing temperatures in
the mountains to 114 degrees on their
hottest day in the desert. “Humidity,
altitude and temperatures were chal-
lenging,” Ron said. “We went through
rain and hail, and below 30 degrees,
the tubes would freeze.”

Matt uses a Newport HT50 vent.
“During the day, he deflated the cuffed
trach, and if we went above 10,000
feet, he inflated it to give him extra
volume,” said Ron. Newport Medical,
Inc. helped sponsor Matt’s journey,
and hosted Matt and his team at their
Costa Mesa, California, headquarters
after he crossed the finish line. Many
Newport employees personally con-
tributed and signed his RV.

Matt got a new wheelchair before
they left, but its top speed was only
3 to 4 miles per hour, so he opted to
use his old chair that could run up to
8 miles per hour. He wore out three
sets of wheelchair tires over the
course of the trip.

One of the biggest challenges they
faced on the trip was satisfying all
the Guinness World Record require-
ments. Every minute of travel had to
be recorded on video, which required
a heavy-duty camera that could be
strapped to the back of the wheel-
chair. All those hours of video had to
be downloaded every night.

“At first, we didn’t realize that the
camera would shut down if the tem-
perature was more than 104 degrees,”
said Ron. “We had to do 8 miles over
one day when we discovered it hadn’t
been recording. We had to keep a log
of all the people we met and ask that
they sign it, and we had to get official
timekeepers to verify the beginning
and end of the trip.”

In addition to the incredible natural
beauty they experienced – from
Niagara Falls to the Grand Canyon
– Ron says that they were struck by
the kindness of people as they crossed
America. While they fell short of their
million-dollar goal, “We raised about
$70,000 for Matt’s Place, so techni-
cally we’re still on the ‘Journey,’”
Ron said. “Matt came down with
pneumonia after the trip, but when
he’s well enough, we will start our
fundraising efforts again.”

Meanwhile, Guinness staff is review-
ing hundreds of hours of video
before certifying the journey as a
world record.