



RACING FOR ALS



**MERCHANDISE
SHIPPED**

**GRANT
LOCATIONS**

**VAN
LOCATIONS**

**EVENT
LOCATIONS**

RESEARCH

ISSUE - ALS is not an incurable disease, it is merely an underfunded one. An ALS patient's life expectancy is 2-5 years, and it manifests differently in each patient.

WHAT HAS BEEN DONE – Racing for ALS has utilized a unique fundraising platform on HDPE (high performance driving experiences) events across the United States to raise capital for ALS research. We support this ALS exploration by financially contributing to two of the foremost authorities on ALS, ALS – TDI and the Duke Neurology - Duke ALS Clinic.

IMPACT

ALS – TDI

ALS Therapy Development Institute (ALS – TDI), is the world's foremost drug discovery lab focused solely on ALS. As a nonprofit biotech they operate without regard to profit or politics. Led by drug development experts and people with ALS, their Watertown, Massachusetts based lab is funded by a global network of supporters like us unified to end ALS. Their mission is to discover and develop effective treatments for ALS. To date, Racing for ALS has donated \$477,172 to further ALS – TDI research.

Duke Neurology – Duke ALS Clinic

Duke ALS Clinic's in-house, no placebo clinical trials and unorthodox reversal studies are conducted at Duke ALS Clinic by Dr. Richard Bedlack with the aim to improve patient survival, quality of life and #ENDALS! With a mere 2-day event in 2022, Racing for ALS was able to donate \$43,744 to help Dr. Bedlack and colleagues continue their mission.

PATIENT ASSISTANCE GRANT & VAN PROGRAMS

ISSUE – The average cost of an ALS patient's medical care is over \$200,000 per year. While insurance might cover some of these costs, patients and their families still often face significant financial burdens.

WHAT HAS BEEN DONE – Racing for ALS created a unique grant/giving program for ALS patients throughout the United States and Canada. Through a simple process ALS patient can apply for grants between \$1,000 - \$2,000 for much needed medical supplies/equipment or handicap accessible updates to their homes. The Van Program currently maintains a fleet of three handicap accessible vans.

IMPACT

Patient Assistance Grant Program – To date, Racing for ALS has granted over \$80,000 to ALS patients all over the United States and Canada to help with their day-to-day needs while fighting this terrible disease.

Van Program - Two of our three vans are currently on loan to ALS patients for their personal use as long as they are needed. When the vans are no longer needed, they are returned to Racing for ALS and then granted to the next family on our waiting list. One of our three vans is currently on a year-long loan to the Joe Martin ALS Foundation where it is used to transport ALS patients to medical appointments, daily errands and family/social gatherings, reducing isolation and financial strain of expensive transportation.

AWARENESS

ISSUE – What the medical community knows today about ALS is about as much as it knew about cancer 100 years ago. This is not okay for a disease that can impact anyone, anytime, regardless of age or gender.

WHAT HAS BEEN DONE – Racing for ALS is dedicated to spreading awareness about not only what ALS is, but also the lack of funding of research to find a cure. We have begun to achieve this goal through our numerous social media avenues (Facebook, Instagram, Twitter and YouTube) with a rapidly growing follower base. Racing for ALS has also provided merchandise (hats, t-shirts, sweatshirts, stickers) for thousands of supporters to help spread awareness visually.

IMPACT – We have increased awareness of how the disease impacts ALS patients and their loved ones through social media with followers in every state and numerous other countries. We have also provided merchandise in 29 states and 2 foreign countries. Our hope is that by someone simply wearing a Racing for ALS t-shirt, or placing a Racing for ALS sticker on their car, we can get the conversation started about what ALS is and how we can work together to cure this horrible disease.

MOVING FORWARD

Since our race against ALS began when Dave was diagnosed in 2017, we have learned a lot about ALS and the needs of the ALS community. Therefore, launching in 2023, all of our events will support 3 different ways to help the ALS community. All 3 of these were chosen specifically by Dave from his research and experiences. They are the **ALS Therapy Development Institute (ALS TDI)**, **Duke Neurology ALS Clinic**, and our **Patient Assistance & Van Program**.

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Patient Assistance Grant & Van Program

The RFALS Pat Assis Fund started in Sept of 2020, and to date has given out \$80,000 in support grants directly to ALS patients, provided a small assortment of ALS medical equipment, and has obtained 3 \$70,000 wheelchair compliant vans for ALS families to use as long as necessary; upon return, they will then be passed to another family on our list. This is our way to help as many people as we can as they fight ALS!

