



Department of Neurology

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Dear Friends,

On behalf of everyone at the Duke ALS Clinic, I want to thank you for your generosity this year. Your donations to the LVH ALS Foundation have again helped us expand our Duke ALS Reversals Research Programs. Here are some highlights:

- We have now confirmed 45 ALS Reversals. We have carefully reviewed records on all of these patients and agree with their diagnosis of ALS, progression to disability and unexpected recovery of lost motor function. Some of these patients were completely paralyzed from their ALS and over time recovered to now have normal motor function.
- We have collected saliva samples on most of these ALS Reversals. These were sent to our colleagues at the University of Miami where DNA was extracted. This DNA was then sent to St. Jude Hospital where it is being analyzed and compared to thousands of patients in a database with more typically progressive ALS. In the next few months we should know if there is a gene that explains ALS Reversals. A similar approach in patients who were resistant to HIV yielded a genetic explanation. That was then rapidly turned into a new treatment which makes everyone more resistant to HIV. Hopefully we can do the same thing with ALS.
- We have detailed environmental exposure questionnaires back from most of the ALS Reversals. We compared their answers to thousands of patients with more typically progressive ALS that signed up for the National ALS Registry. Surprisingly, we learned that ALS Reversals are more likely to have worked with wood than patients with ALS who did not get better. We are now designing studies to try and understand how chemicals in wood might “immunize” people against ALS.
- Six of the 45 ALS Reversals were taking some form of curcumin during their recovery. This interesting molecule is found in spices like turmeric and curry powder, and has multiple mechanisms by which it could alter ALS progression. We are now very close to opening a widely-inclusive, entirely-virtual trial of curcumin in patients with ALS.
- In 2020, we will be testing several other new “outside the box” ideas. For example, it was recently shown that altering the microbiome (the family of bacteria that live in our guts) can dramatically change ALS progression. We will be comparing the microbiome in ALS Reversals to that of patients with more typically progressive ALS. If we find differences we will try and alter the microbiome in patients toward one associated with ALS Reversals.

Much of the innovative, exciting research work we are doing here would not be possible without your support. On behalf of our entire team, thank you for your partnership.

With gratitude,

richard bedlack

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