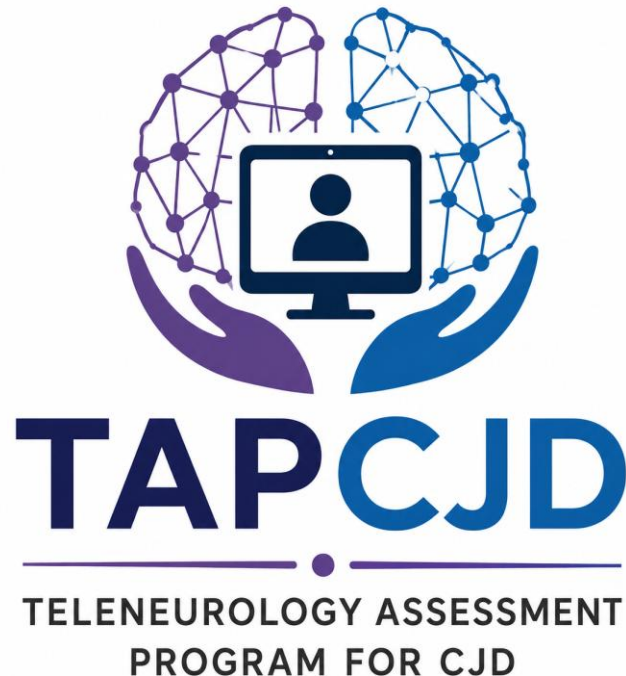


Teleneurology Assessment Program for CJD (TAPCJD)

Empowering Families to Participate in Prion Disease Research

Brian Appleby



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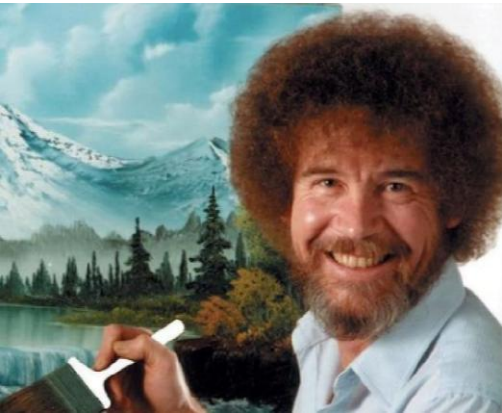
What is TAPCJD?

- Mission:
 - Gather clinical data remotely, for research & surveillance
 - Study the natural history of the disease
 - Study caregivers
- Approach: Started in 2017 to conduct research without requiring travel
- Partnership: NPDPS, CJD Foundation



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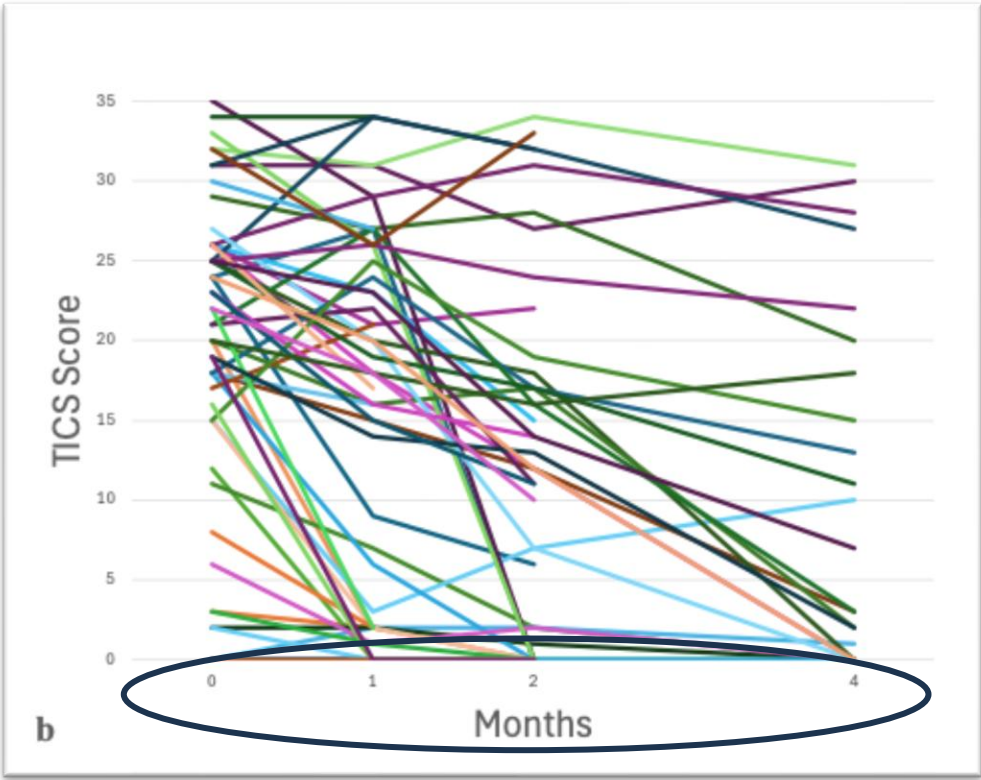
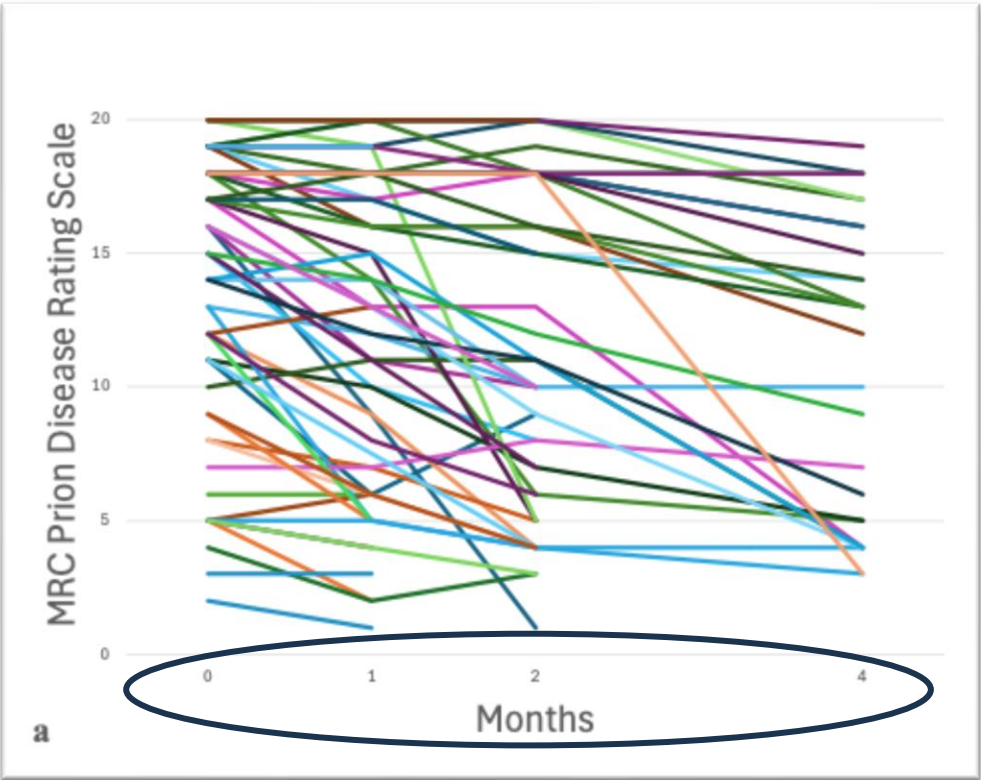
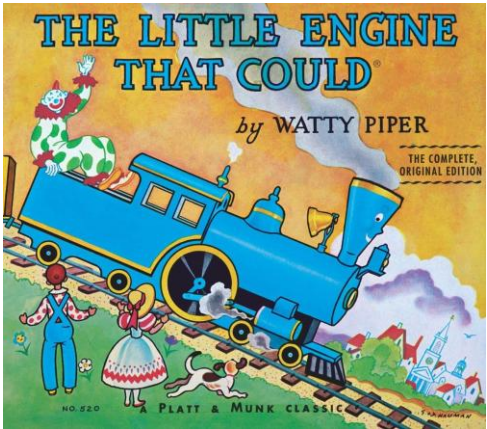
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Why TAPCJD is so important

Jun 2, 2026 • ericminikel • Cambridge, MA

This blog post is a call to action. Patients newly diagnosed with prion disease in the U.S. have an opportunity to make a meaningful contribution to research by participating in Brian Appleby's [Teleneurology Assessment Program in CJD](#), or TAPCJD for short. In this post, I'll talk about this moment in prion disease research, what we need, and how participating in TAPCJD can help.



How TAPCJD Works

- Eligibility: Diagnosis of probable prion disease, have a study partner, internet access
- Schedule: Baseline visit, follow-up visits every 1–3 months
- Activities: Talk about symptoms & changes, complete questionnaires, visits are longer initially, shorter later
- Patient Friendly: Flexible location, timing of visit tasks, discuss the disease, access to all findings, average satisfaction of 4.8/5.



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Closing the Data Gap

Assessment Modality	Accessibility	Data Standardization	Longitudinal Data
In-Person Visits	Poor	High	Low
Medical Record Review	High	Poor	Moderate
Teleneurology (TAPCJD)	High	High	High

Other caveats:

- Access to diagnostic data (CSF, brain MRI images)
- High brain donation rates
- One major downside: no longitudinal biomarkers

Is the MRC-PDRS a Good Measurement Tool?

Table 5. Convergent Validity – Pearson Correlations between MRC-PDRS Total Scores and Concurrent TICS

Visit	N	MRC-PDRS Total (<i>r</i>)	MRC-PDRS Cognitive Component (<i>r</i>)
1	95	0.77	0.83
2	59	0.81	0.78
3	47	0.86	0.89
4	27	0.80	0.74

Track with similar measurements?



Table 6. Divergent Validity – Pearson Correlations between MRC-PDRS and NPI-Q

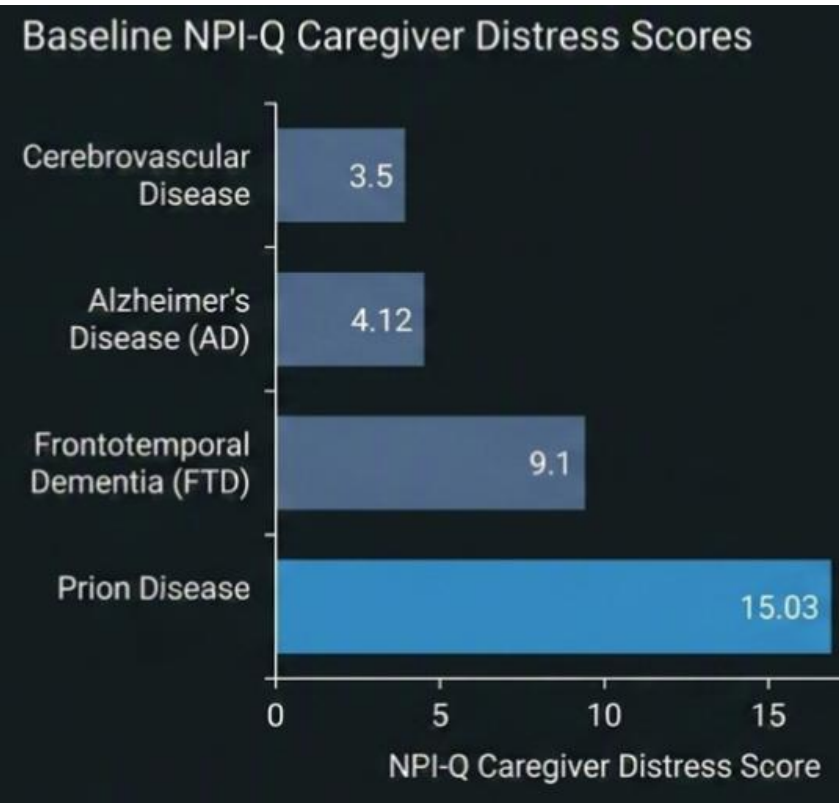
Visit	N	NPI-Q Symptoms (<i>r</i>)	NPI-Q Severity (<i>r</i>)	NPI-Q Caregiver Distress (<i>r</i>)
1	96	-0.07	-0.12	-0.10
2	56	0.03	-0.05	0.00
3	49	0.05	-0.07	0.02
4	27	0.12	0.02	0.20

Doesn't track with dissimilar measurements?

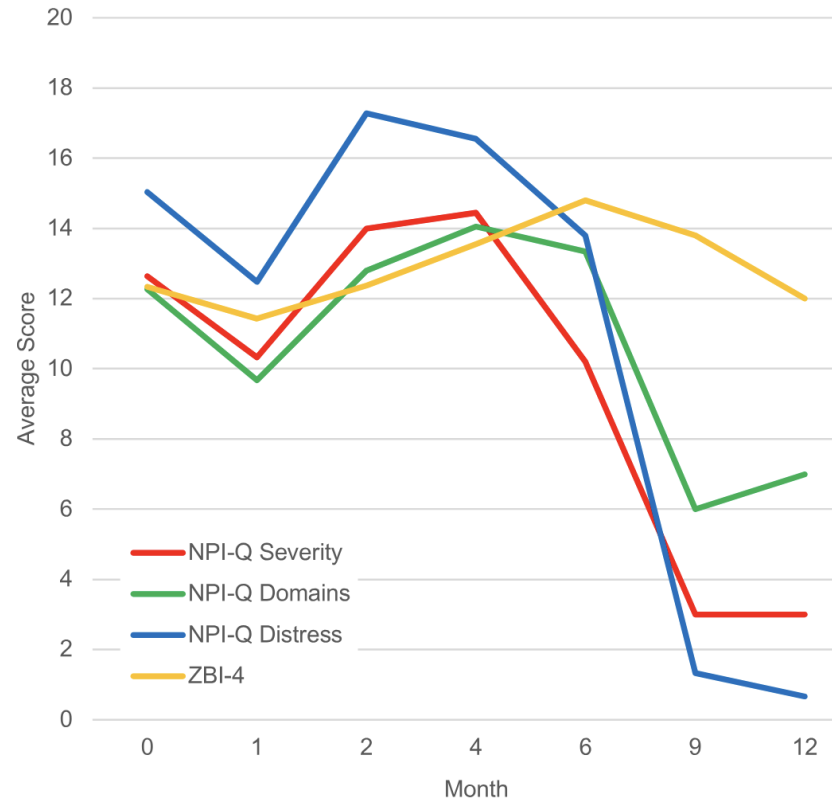


A 1-3 point change on the MRC-PDRC seems meaningful (5-15% change)

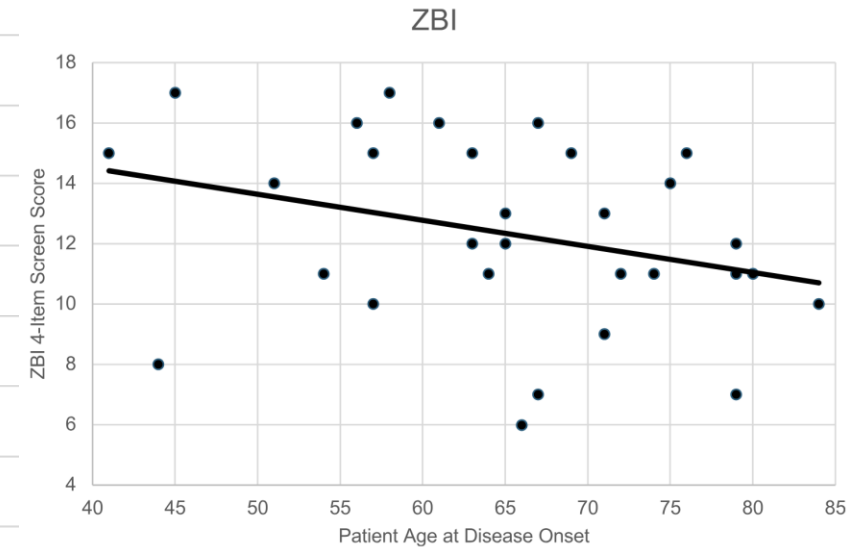
TAPCJD Studies Patients **AND** Caregivers



Caregiver distress caused by neuropsychiatric symptoms far surpassed other dementias



Burden remained high over time despite improvement in neuropsychiatric symptoms



Caregiver burden was inversely related to patient age

TAPCJD: The Ultimate Goal

- Gather clinical data to inform the best possible clinical trials
- Create a natural history dataset to serve as an external control group to minimize or eliminate the use of placebo arms in clinical trials
- More patients get access to experimental drugs
- Helps prevent the “too many trials, too few participants” scenario



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The Gift of TAPCJD Participation

- Not everyone is eligible for a clinical trial after diagnosis
- **EVERYONE** is eligible for TAPCJD after diagnosis
- A TAPCJD participant **IS** a clinical trial participant
- TAPCJD participants are part of a unique dataset not available anywhere else
- We share deidentified TAPCJD data with people who are planning for a different future of prion disease



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Thank You!

- TAPCJD participants & study partners
- Funders: Cookie Stivison & CJD Foundation
- Collaborators: Leah Leidy, Ionis (Rob Pulido & Aaron Yaras), John Martin, Eric Minikel



Katie Glisic, MA



Ali Kovacevich, MD

By documenting the journey today, we are paving the way for a treatment tomorrow.



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