NEURODEGENERATIVE DISORDER

CASE STUDY

# Amyotrophic Lateral Sclerosis (ALS)

## METHODOLOGY STUDY

This ALS methodology study was being conducted to assess a set of potential outcome measures to determine their relative utility for incorporation into future ALS proof-of-concept studies. For patients, participation offered them the opportunity to help advance knowledge about the disease and contribute to research that may help the ALS community. However, as an observational study, recruitment and engagement posed a challenge for the study sponsor, especially in the face of competing interventional studies.

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|---|---|---|
| **18** SITES | **250** PATIENTS | **24** MONTH PARTICIPATION |

## COUNTRIES

9

## CHALLENGES

Because this was an observational study, outreach materials needed to engage patients and their loved ones with messages of altruism, inspiration, and support.

To assess disease progression, patients needed to receive a battery of electrophysiological, clinical, and functional tests – all potentially physically taxing. BBK needed to minimize patient burden with its RSG® Arrive and RSG® Card programs.

Site staff needed to be unburdened from travel and reimbursement efforts to not only implement a complex study design, but also to focus on study participants and their needs.

## KEY TAKEAWAY

This observational study included 7 visits to the study site and 11 telephone calls over 2 years. To make the study experience as convenient as possible – for a patient population that was giving so selflessly to the ALS research community – RSG® Arrive successfully removed travel burden, while RSG® Card ensured patients weren't paying out-of-pocket for significant expenses.

## KEY TACTICS

- Outreach Materials
- RSG® Card
- RSG® Arrive
- Advertising

## TACTIC PERFORMANCE

**0%**

WITHDRAWAL RATE

### RSG ARRIVE

The withdrawal rate among RSG® Arrive users was 0%, compared to a withdrawal rate of 4.37% among RSG® Arrive non-users.

**100%**

SITE USAGE

### RSG CARD

RSG® Card was embraced and utilized by all 18 study sites. The reimbursement program effectively reduced burden among site staff, allowing them to spend more time on patient care.

**421**

VISITS REIMBURSED

### RSG CARD

RSG® Card was utilized to reimburse and support study participants for over 420 study visits. Immediate and effective reimbursement was important to ensure long-term patient engagement.

**56**

SEM REFERRALS GENERATED

### SEARCH ENGINE MARKETING (SEM)

A form of online advertising, search engine marketing, or SEM, generated 56 referrals for 5 sites in the United States.

bbk The Patient Experience Company™

+1.617.630.4477 info@bbkworldwide.com bbkworldwide.com