Recruitment in Rare. Myth Debunked!

BIONEWS
WE ARE RARE.

Presenters

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Objective

Recruiting patients affected by rare diseases is hard.

In response to a need voiced by our audience (1 million rare patients and their care circle over 60 communities) we launched a "virtual meeting ground" to connect them to ongoing sponsored clinical trials. Our hypothesis was that leveraging the trusted relationship with our audience and bringing clinical trial opportunities where patients already consume healthcare information, would simplify, and speed up recruitment.

Design

Idiopathic Pulmonary Fibrosis (IPF), Sarcoidosis (SAR) and Sjogren's Disease (SJO) were the rare disease communities we selected based on a) level of engagement; b) number of patients in our audience; c) number of trials recruiting patients per clinicaltrials.gov.

We executed recruitment campaigns for 5 clinical trials in those diseases, with both pragmatic and non-pragmatic study designs as well as traditional and decentralized/hybrid models.

Results

For the 3 IPF trials, the referrals generated in our 8-16 weeks recruitment campaigns converted in 42 enrolled (trial 1); 35 randomized (trial 2), 33 referred (trial 3, ongoing).
For SAR in African Americans: 47 enrolled; for SJO: 11 randomized.

Conclusion

We keep witnessing the paradox of rare patients desperately looking for trials and pharma companies not finding patients. In part, it is because we operate in an industry where the interaction with patients is often transactional and confined to the recruitment phase of clinical trials.

We demonstrated that when we engage continuously, operate on an existing foundation of trust, and bring trial opportunities where patients consume healthcare information, recruitment is a lot faster.

CLINICAL TRIAL RECRUITMENT PERFORMANCE

BIONEWS CLINICAL	Idiopathic Pulmonary Fibrosis (IPF) Study*	Sarcoidosis*	Sjogren's Syndrome**
Targeting	All comers	African Americans	All comers
Email Open Rate	59.29%	34.68%	57.29%
Email Click Rate	15.00%	4.25%	18.58%
Click Referral Rate	N/A	N/A	10.29%
Clicks Enrollment Rate	20%	15.46%	TBD
Completed Screening Questionnaire and Referred to Trial Site	N/A	N/A	290
Enrolled/Randomized In Trial	42	47	11

*8 week duration; completed; all US; decentralized
**33 Sites; 16 week duration; specific geographies in US; traditional;