

# What makes a rare disease community powerful?

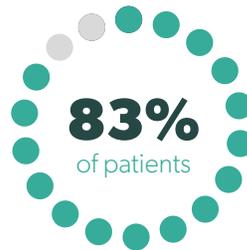


## And why does it matter?

*“He who masters the power formed by a group of people working together has within his grasp one of the greatest powers known to man.”*

**Idowu Koyenikan**

*All You Need Is a Ball: What Soccer Teaches Us About Success in Life and Business*



would provide feedback to drug developers<sup>1</sup>



would choose treatments from companies that are engaged with them over those that are not<sup>1</sup>



The FDA actively seeks PAC perspectives on disease impact and benefits and risks of treatments from “identifiable patient communities”

## Powerful rare disease communities can:



Improve drug development and commercialization



Influence regulatory decisions



Shape treatment paradigms



Educate others about the disease

PAC = patient, advocate, and caregiver.

<sup>1</sup> Salesforce. 2017 Connected Patient Report: The trail map for understanding today's digital patient – A Harris Poll. San Francisco, CA, USA, 2017. Available at: <https://a.sfdcstatic.com/content/dam/www/ocms-backup/assets/pdf/industries/2017-connected-patient-report.pdf>. Accessed August 4, 2020.

onevoice has optimized the value of powerful rare disease communities



Safe and secure place for diverse stakeholders to connect



Curated disease, treatment, and trial information



Opportunities to generate and share data, information, and insights to advance care and drug development

## Real-world examples of the impact of powerful onevoice rare disease communities

### Powerful onevoice community influences FDA response package



### Powerful onevoice community accelerates trial recruitment



**Pharma** needs to accelerate trial enrollment



**rareLife** recruits through strong onevoice community using a variety of tools



**Community** responds quickly—far exceeding industry response benchmarks!



**Trial** enrollment is boosted and delays are avoided