

# 2022 END OF YEAR IMPACT SUMMARY



## Our Mission to Find Treatments Faster

The Kabuki Syndrome Foundation (KSF) is a nonprofit organization with the sole purpose of accelerating Kabuki syndrome research that leads to a treatment or cure. The foundation is led by professionals who are business leaders in their fields, allowing us to access resources across multiple industries to help drive activities that support our mission. More importantly, we are parents, aunts, and uncles of children who are affected by Kabuki syndrome. **We understand that in order to achieve success, patients and families must be at the core of our mission.**

With the first commercial clinical trial expected to begin in 2023, now is the time for the most important push forward in Kabuki syndrome research. We are committed to developing and executing a research roadmap that supports multiple therapeutic strategies to ensure treatment options will be available in the future. **Together**, we CAN find treatments faster.

## Key Metrics

# \$125K

Grant awarded to develop a tool that measures neurological symptoms in Kabuki syndrome across institutions and clinical trials

# 95

Clinicians and researchers from 35 countries engaged in our global network that creates and promotes collaboration

# 67

Individuals enabled to participate in-person in a research study that could lead to a new diagnostic tool for Kabuki syndrome

# \$45K

included travel funds that enabled over a dozen new families to participate in research and see an expert in-person

# 97

Crowdsourcing survey responses that enabled planned expansion of KKI's diet trial, the only current clinical trial in Kabuki syndrome

# 450

Participants at our annual research conference from 36 countries

# 19

Families recruited for a research project dedicated to creating a patient-centered outcome measure for clinical trials



KSF collecting digital fingerprints at a community event

# \$420,000

Raised in 2022 thanks to the generosity of our community, donors, experts, and volunteers. Your support has made it possible for us to start funding research that moves us closer to our goal of treatment options for everyone with Kabuki syndrome.

## 2023 Priorities

### AWARDING

Research grants that move our community closer to treatments and enforce collaboration

### LAUNCHING

Global #KabukiCount to find record number of people with Kabuki syndrome and show the strength of our community

### DEVELOPING

The roadmap to therapeutic options for Kabuki syndrome utilizing an experienced rare disease research team