2023 End of Year Snapshot

Kabuki SYNDROME FOUNDATION

Thank you for joining us this year. Your ongoing support helps find treatments faster.

$1,260,000 Secured to Create Biomarkers & Enable Testing of Treatments in Clinical Trials

The Kabuki Syndrome Outcome measures and biomarkers Consortium (KSOC) is a collaborative research study funded and managed by the Kabuki Syndrome Foundation (KSF).

- Aim: Develop 3 biomarkers for Kabuki syndrome over the next two years to fast-track treatments.
- Progress: First recruitment goal (90 families) exceeded within 24 hours of launch.

$500,000 Raised for Research at Inaugural Gala, "Quest for a Cure" in NYC

This seminal fundraising gala brought together a sold-out crowd of 300 local supporters and raised over half a million for Kabuki syndrome research. Thank you to to every supporter and the event chairs!

$150,000 Discovery Grant Awarded to Unlock New Treatment Targets for Kabuki Syndrome

After reviewing 9 excellent applications, KSF awarded this grant to Dr. Hans Bjornsson, Johns Hopkins and University of Iceland; Dr. Karl Broman, University of Wisconsin; and Dr. Agnes Ulfig, University of Iceland! This team plans to uncover why symptom severity varies so greatly to unlock new treatment targets.

95% OF RARE DISEASES DO NOT HAVE TREATMENTS.
THOSE THAT DO WERE ENABLED BY ORGANIZED AND ACTIVELY FUNDRAISING COMMUNITIES LIKE THE KABUKI SYNDROME FOUNDATION.

817 People with Kabuki Syndrome *Counted* at KabukiCount.com

The global Kabuki syndrome patient census, Kabuki Count, is the world's largest collection of Kabuki syndrome data including mutation type, age, and contact information. This tool enables KSF to mobilize families to participate in research and clinical trials.

Thank YOU.

With your support, we've made significant progress this year. KSF has raised over $2 million in support of LEAP, our roadmap to treatments. At least 8 potential treatments for Kabuki syndrome are in the pipeline that can be accelerated with additional funding. Together, we can find treatments faster.

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