COMBINEDBrain Received the Global Genes 2022 Health Equity RARE Patient Impact Grant

NASHVILLE, TENNESSEE, UNITES STATES, September 6, 2022 /EINPresswire.com/ -- COMBINEDBrain Received the Global Genes 2022 Health Equity RARE Patient Impact Grant

COMBINEDBrain takes steps to break down language barriers perpetuating health inequity in research by translating patient registry informed consent and health surveys into three languages.

COMBINEDBrain (Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders), a non-profit organization of patient advocacy groups representing rare genetic neurodevelopmental disorders, is pleased to announce they have been awarded a Global Genes Health Equity RARE Patient Impact Grant which will be used to translate the ClinGen Health Surveys into French, German, and Italian, in addition to Spanish and English which are currently available. These additional languages will allow more rare disease patients from around the world to participate in research.

This spring, as members of COMBINEDBrain met to plan the launch of natural history studies, it became apparent that language was a major barrier to recruiting patients from all parts of the world. Without exception, these groups found that offering English-only study documents delayed community engagement and enrollment.

Many families of people with rare diseases express strong interest in sharing their experiences. Patients and caregivers understand the importance of natural history research in improving understanding of rare and ultra-rare diseases. Many organizations in COMBINEDBrain are working with Across Healthcare's Matrix to collect patient-centered data. Matrix has platform menus and navigation tools available in Spanish, French, German, and Italian. However, the consent forms and surveys were not available in multiple languages. Many families for whom English is not their first language expressed difficulty understanding the informed consent and the health survey questions.

"For individuals and families facing a rare disease, the journey is already incredibly difficult," said Craig Martin, CEO of Global Genes. "For those in historically underserved or marginalized communities, the struggle is often even more challenging. Through our Impact grants, we are pleased to support leaders on a global scale with resources to more effectively collect, create and share information and to help lessen burdens and improve experiences and outcomes for

underrepresented members of the rare disease community."

The Global Genes health equity grant will help to break down this language barrier and improve health equity in research and treatment of rare neurodevelopmental disorders. The ClinGen surveys are a National Institutes of Health (NIH)-funded resource designed to collect consistent health histories for use in precision medicine and research. The grant will fund medical-grade translation of these respected surveys by LanguageLink into languages other than English. COMBINEDBrain plans to share the translations back to the ClinGen Project for dissemination around the world. Breaking down language barriers is necessary in order to include the experience of diverse populations in health research. Increasing diversity leads to improved research, diagnosis, standards of care, and a more comprehensive and inclusive understanding of disease and the patient journey.

"COMBINEDBrain represents neurodevelopmental disorders, but the impact of these translations will go far beyond our scope, to help increase diversity in research on genetic disorders around the world. I am so proud of the leaders of our member groups, who had the vision to be inclusive and collaborative, and so grateful to Global Genes for incentivizing this work."

"Within rare disease populations, there is a dire need to be as inclusive as possible by breaking down any barriers. In the past, a huge barrier has been providing data collection platforms only in English. Our Matrix rare disease platform was architected to have multilingual support at its core," states Jason Colquitt, CEO of Across Healthcare. "This grant is exciting and promising since it will allow us to unlock the ClinGen surveys for French, German, and Italian speaking patients and caregivers who would have previously never been able to participate without these translations. This is a huge win for everyone!"

COMBINEDBrain non-profit 501c3 organization with a mission to speed the path to clinical treatments for people with severe rare genetic neurodevelopmental disorders: https://combinedbrain.org

ASXL Rare Research Foundation
CACNA1A Foundation
Coalition to Cure CHD2
CureSHANK
DYRK1A Syndrome International Foundation
FamiliesSCN2A Foundation
Foundation for Hao-Fountain Syndrome
FOXG1 Research Foundation
Glut1 Deficiency Foundation
GRIN2B Foundation

iDefine Foundation (Kleefstra)
KIF1A.ORG
NR2F1 Foundation
SATB2 Gene Foundation
SETBP1 Society
SGS Foundation
SLC6A1 Connect
Shwachman-Diamond Syndrome Alliance Inc
The Yellow Brick Road Project (HNRNPH2)

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