LETTER: NEW OBSERVATION

# DBSMatchMaker: Connecting Clinicians Globally for Deep Brain Stimulation in Rare Diseases

Umar Zubair, cand. med.,[1] Habibah A.P. Agianda, MD,[1] Kathryn Yang, MBChB, FRCPC,[1] Amy Tam, BSc,[1] Joshua Rong, BSc,[1] Carolina Gorodetsky, MD, MSc,[2,3] Shekeeb S. Mohammad, MBBS, FRACP, PhD,[4] Juan Darío Ortigoza-Escobar, MD, PhD,[5] and Darius Ebrahimi-Fakhari, MD, PhD[1*]

The field of genetic movement disorders is rapidly evolving. Most manifest during childhood as hyperkinetic conditions with substantial morbidity. Although all are rare diseases, many emerging entities are ultrarare, affecting fewer than 100 individuals worldwide. Deep brain stimulation (DBS) is an effective treatment for dystonia and other hyperkinetic disorders, and evidence continues to emerge supporting its use across an expanding range of monogenic conditions, sometimes with remarkable benefit (examples published in 2024[1-6]). This underscores the importance of considering DBS early in such cases.

Certain conditions, such as *TOR1A*-related dystonia, already have well-established indications for DBS. Meanwhile, a growing list of monogenic diseases (*ACTB*, *ADCY5*, *EIF2AK2*, *GNAL*, *GNAO1*, *GNB1*, *KMT2B*, *PANK2*, *SGCE*, *TAF1*, *THAP1*, *UBA5*, *VPS16*) should be prioritized for DBS evaluation. Despite this, many rare movement disorders remain poorly understood with respect to their response to DBS and optimal patient selection. Even highly specialized centers often have limited experience, and decision-making is frequently guided by anecdotal observations only. Informal collaborations among specialists, as well as groups like the DBS Think Tank, the MDS Pediatric Movement Disorders Special Interest Group, and the ERN-RND Dystonia Working Group, offer valuable forums for knowledge sharing. However, these platforms may not be readily accessible to everyone and lack a formal structure.

There is, therefore, a pressing unmet need to

1. Develop a rapid and accessible platform that connects clinicians treating the same rare indications with DBS and
2. Create a sustainable platform to aggregate shared experiences and foster collaboration.

In the field of genetics, a similar challenge in the discovery of novel disease-associated genes has been addressed by GeneMatcher, with tremendous success.[7] Drawing inspiration from this model and incorporating feedback from DBS communities across different health-care settings, we developed DBSMatchMaker (https://www.dbsmatchmaker.com/) (Fig. 1).

DBSMatchMaker connects clinicians worldwide enabling them to evaluate the appropriateness of DBS for patients with monogenic movement disorders of all ages. The workflow is straightforward and requires minimal data: Information about the genetic condition, the anticipated or implanted DBS target, and consent to share the email contact for the purpose of matching (Fig. 1). Optionally, response to DBS is recorded using a simple three-point scale. Upon submission, the system automatically queries the database, and staff verify contributors' institutional affiliations to ensure entries are unique and free of duplication. If a match is found, the submitters are notified via email. If no match is identified, the gene of interest remains in the system for future queries. DBSMatchMaker adheres to strict safety and privacy protocols: The database is not searchable, and no identifiable data are collected. Genes entered in the database are displayed on the homepage along with submitter-rated treatment responses (Fig. 1). We hope that DBSMatchMaker's user-friendly interface, minimal mandatory data requirements, and direct relevance to patient care will reduce barriers and encourage participation from centers worldwide.

[1]Movement Disorders Program, Department of Neurology and F.M. Kirby Neurobiology Center, Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA; [2]Division of Neurology, The Hospital for Sick Children, Toronto, Ontario, Canada; [3]Department of Pediatrics, University of Toronto, Toronto, Ontario, Canada; [4]Children's Hospital at Westmead Clinical School and Kids Neuroscience Centre, Sydney Medical School, Faculty of Medicine and Health, University of Sydney, Westmead, New South Wales, Australia; [5]Movement Disorders Unit, Pediatric Neurology Department, Institut de Recerca, Hospital Sant Joan de Déu Barcelona, Barcelona, Spain



*Correspondence to: Dr. Darius Ebrahimi-Fakhari, Movement Disorders Program, Department of Neurology and F.M. Kirby Neurobiology Center, Boston Children's Hospital, Harvard Medical School, 3 Blackfan Circle, Boston, MA 02115, USA; E-mail: darius.ebrahimi-fakhari@childrens.harvard.edu

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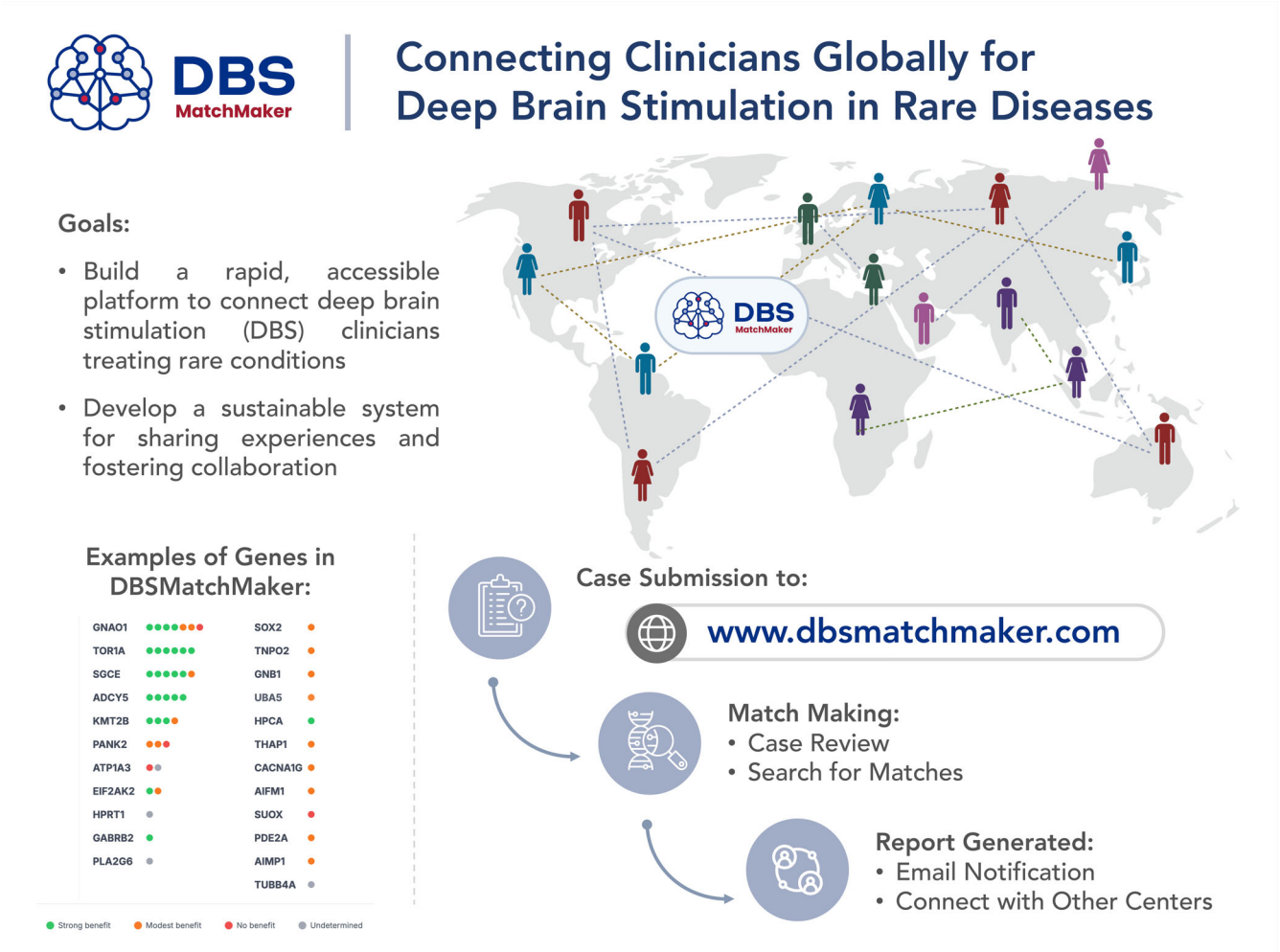


**FIG. 1.** DBSMatchMaker (https://www.dbsmatchmaker.com/): A platform designed to connect clinicians worldwide, enabling the evaluation of DBS (deep brain stimulation) suitability for patients of all ages with genetic movement disorders. This freely accessible website facilitates connections between clinicians treating rare movement disorders using DBS. The workflow is streamlined and requires minimal data: Clinicians provide genetic information, the DBS target, and email consent for communication. Optionally, DBS response can be recorded using a simple three-point scale (strong, modest, or no therapeutic effect). Upon submission, the system automatically queries the database and notifies submitters via email if a match is found. If no match is identified, the data remain available for future queries. The platform adheres to stringent safety protocols, ensuring no identifiable data are collected. Genes entered are displayed on the homepage alongside submitter-rated treatment responses. Figure was, in part, created using BioRender.com. [Color figure can be viewed at wileyonlinelibrary.com]

In summary, by fostering global collaboration, DBSMatchMaker aims to enhance patient selection, counseling, treatment strategies, research, and overall outcomes for individuals with rare genetic movement disorders. We are excited to see this platform grow with each submission by the community, making it increasingly valuable for future users. ■

**Author Roles:** D.E.-F. conceptualized and designed the DBSMatchMaker. K.Y., C.G., S.S.M., and J.D.O.-E. provided critical feedback and refined the platform. U.Z. and H.A. built the DBSMatchMaker website and database. K.Y., A.T. and J.R. organized the study protocol. D. E.-F. drafted the original manuscript, with contributions from other authors. All authors contributed to the final draft of the manuscript.

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## Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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