BRIEF REPORT

DBSMatchMaker: Global Uptake and Insights from the First Year of a Collaborative Deep Brain Stimulation Platform

Joshua Rong, BSc, Katerina Bernardi, MD, Darius Ebrahimi-Fakhari, MD, PhD, and Kathryn Yang, MBChB, FRCPC*

ABSTRACT: Background: DBSMatchMaker (https://www.dbsmatchmaker.com), launched publicly in December 2024, is a freely accessible, web-based platform that connects clinicians treating rare genetic movement disorders with deep brain stimulation (DBS).
Objective/Methods: To characterize the first year of adoption and early clinical impact of DBSMatchMaker. We evaluated global uptake, usage patterns, and early insights from December 2024 to December 2025. We analyzed aggregate, deidentified submissions; required fields included genetic diagnosis and DBS target, with optional three-point treatment response ratings.
Results: Forty-one clinicians from 39 institutions across 20 countries submitted 158 unique cases spanning 58 monogenic movement disorders, most commonly *GNAO1*-, *KMT2B*-, *PANK2*-, *ADCY5*-, and *SGCE*-related disorders. Among entries with outcome ratings, 84.6% reported strong or moderate benefit. The system generated 614 clinician matches, including several that led to changes in management or multicenter research case series.
Conclusions: Early adoption highlights global engagement and clinical utility. DBSMatchMaker serves as a living repository that lowers barriers to data sharing and supports data-driven DBS decision-making. © 2026 International Parkinson and Movement Disorder Society.

Key Words: deep brain stimulation; genetic dystonia; monogenic movement disorders; neuromodulation; pediatric movement disorders

In our initial report introducing DBSMatchMaker, we described the development of a clinician-driven platform, modeled on GeneMatcher, to connect practitioners treating rare genetic movement disorders with deep brain stimulation (DBS).[1] The need for such a tool is underscored by the ultra-rare nature of many early-onset movement disorders and the lack of systematic data guiding patient selection, target choice, and counseling.

In this article, we summarize the first year of DBSMatchMaker following its public launch in December 2024, focusing on global uptake, case mix, outcomes as reported by contributing clinicians, and lessons learned from early implementation.

Materials and Methods

Platform and Data Collection

DBSMatchMaker (https://www.dbsmatchmaker.com) is a secure, web-based platform that allows clinicians to submit deidentified cases of monogenic movement disorders evaluated or treated with DBS. Mandatory fields include the causative gene and DBS target (planned or implanted). Optional fields capture age at implantation,

Movement Disorders Program, Department of Neurology, Boston Children's Hospital, Boston, Massachusetts, USA

***Correspondence to:** Dr. Kathryn Yang, Department of Neurology, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115, USA; E-mail: kathryn.yang@childrens.harvard.edu

Darius Ebrahimi-Fakhari and Kathryn Yang contributed equally to this work.

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DBS indication, and clinician-rated treatment response on a three-point scale (strong benefit, moderate benefit, no benefit, corresponding to ≥50% improvement, 25%–49% improvement, and <25% improvement on the Burk-Fahn-Marsden Dystonia Rating Scale in the case of dystonia). The platform records whether a case is "implanted" or "not yet implanted" at the time of entry.

For this analysis, we included all submissions between December 2024 and December 2025. Test entries and obvious duplicates (eg, identical gene, target, center, and internal identifier submitted within minutes) were removed. Institutional affiliation of each contributor is verified by platform staff to ensure authenticity and prevent duplicate accounts.

User Feedback

User feedback was obtained through free-text comment fields on the submission form, direct e-mail correspondence, and discussions during virtual DBSMatchMaker and DBSClub seminars. Feedback was reviewed periodically by the core study team and categorized into themes (eg, usability, data fields, privacy, follow-up).

Analysis

Aggregate, deidentified data were summarized descriptively. We report numbers and proportions for participating clinicians and institutions, geographic distribution, genetic diagnoses, DBS targets, and response ratings. Where relevant, we highlight patterns in response by gene and target; given sample sizes and the self-reported nature of outcomes, no formal statistical comparisons were performed.

Data Sharing

Aggregate, deidentified data underlying this report are available from the corresponding author on reasonable request.

Results

Global Outreach

As of December 2025, DBSMatchMaker registered 41 clinicians from 39 institutions across 20 countries (Fig. 1A). Participating sites span six continents and include both pediatric and adult DBS centers in North America (23.1%), Europe (38.5%), Asia (15.4%), South America (10.2%), Oceania (10.2%), and Africa (2.6%). This rapid uptake within 12 months highlights the unmet need for structured, cross-institutional communication in rare movement disorders.

Case Distribution

Across all participating centers, 158 unique cases were submitted, encompassing 58 distinct monogenic movement disorders. Five centers submitted the majority of cases, with 25 centers contributing a single case only to date. The five centers with the highest number of submissions were the San Borja Arriaran Hospital (Santiago, Chile), Hospital for Sick Children (Toronto, ON, Canada), Hospital Sant Joan de Déu (Barcelona, Spain), Boston Children's Hospital (Boston, MA, USA), and The Children's Hospital at Westmead (Sydney, Australia). The most frequent genetic diagnoses involved *GNAO1* (13.3%), *KMT2B* (11.4%), *PANK2* (8.9%), *TOR1A* (7.6%), *THAP1* (5.1%), *ADCY5* (4.4%), and *SGCE* (3.8%) together accounting for 54.5% of all submissions (Table 1). Thirty-seven genes were submitted only once and thus remain unmatched to date, reinforcing the ultra-rare nature of these disorders and the importance of global collaborative platforms to connect isolated cases. The list also includes genetic disorders for which outcomes with DBS have not, to our knowledge, been previously documented in the literature.

The globus pallidus internus (GPi) was the predominant target (95.1%), with only four cases targeting the subthalamic nucleus. Among entries with completed response ratings, 84.6% reported moderate or strong benefit from DBS. Of the seven most common indications, a strong benefit was recorded in 83% of *SGCE*, 75% of *TOR1A*, 67% of *KMT2B*, 57% of *ADCY5*, 52% of *GNAO1*, 50% of *THAP1*, and 21% of *PANK2* cases (Fig. 1B). These findings are broadly consistent with emerging evidence supporting GPi stimulation in genetic dystonias and related hyperkinetic disorders.[2-5]

Collaborative Impact

During the observation period, the platform facilitated 614 successful clinician matches (defined as connections or correspondence between clinicians treating patients with the same gene or closely related phenotype). These matches supported consultative discussions regarding candidacy, timing, and programming, and enabled data sharing in real time.

Twenty-six cases were initially entered as "Not Yet Implanted." At least one of these cases proceeded to DBS following collaborative review via DBSMatchMaker. Multiple matched users have initiated or are coauthoring joint case series on *GNAO1*- and *ADCY5*-related disorders, illustrating the platform's potential to catalyze multicenter observational studies.

Platform Evolution

Feedback from contributors prompted several technical and structural refinements, including:

- Removal of date of birth from the submission fields to further minimize reidentification risk

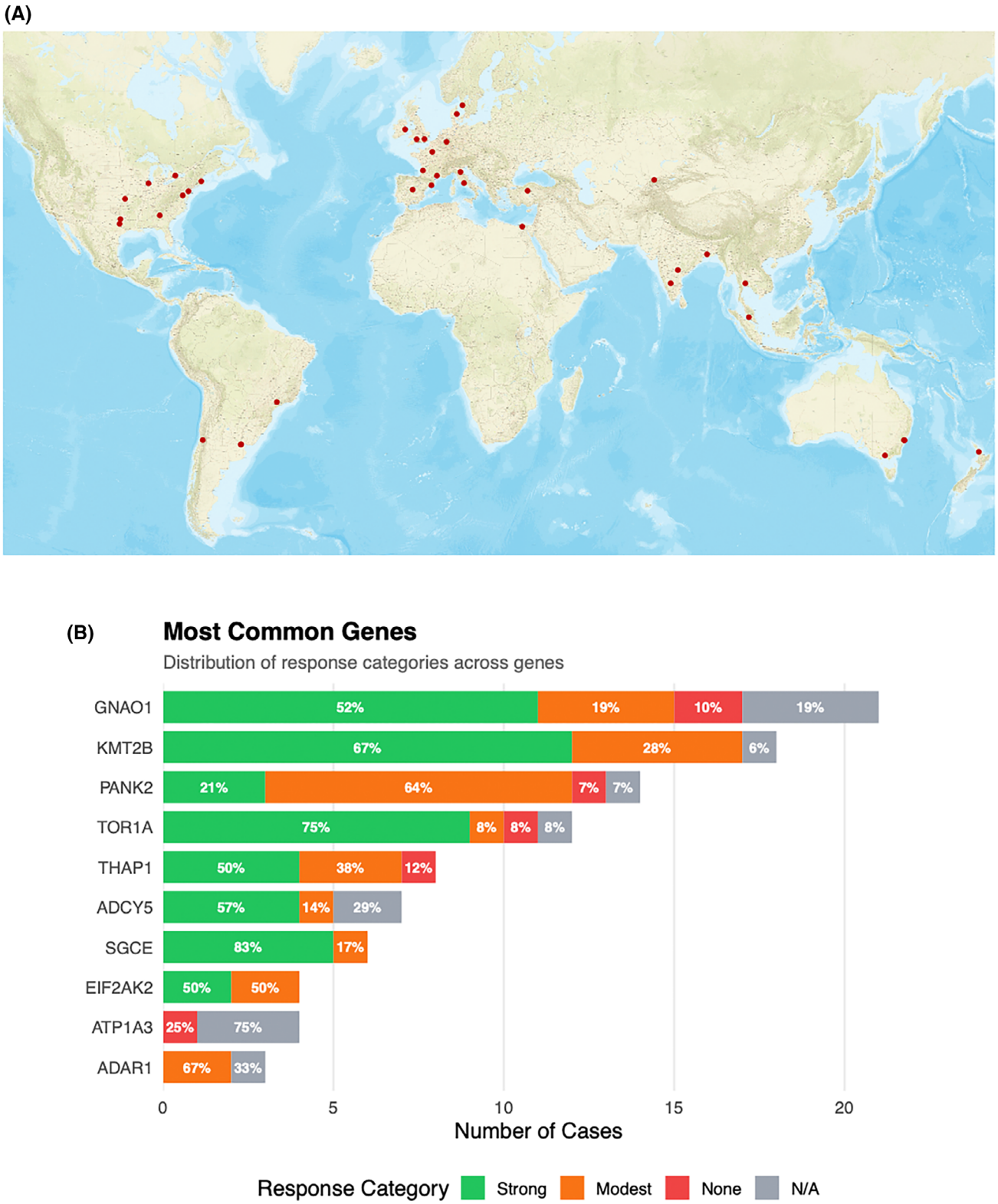

FIG. 1. (**A**) Global distribution of contributing clinicians and institutions. Geographic distribution of the 39 institutions contributing to DBSMatchMaker (dbsmatchmaker.com) during its first year (December 2024–December 2025). Participating clinicians span six continents and include deep brain stimulation (DBS) programs for pediatric and adult patients across North America, Europe, Asia, South America, Oceania, and Africa. (**B**) Clinician-reported DBS response across the most common genetic diagnoses. Submitter-reported treatment response among the seven most frequently submitted genetic movement disorders. Ratings use a three-point scale (strong, moderate, no benefit). [Color figure can be viewed at wileyonlinelibrary.com]

TABLE 1 *List of all genes for which clinicians reported cases with prior deep brain stimulation implantation*

All implanted cases				
Genes only submitted under "Not Yet Implanted" have been excluded				
GNAO1	KMT2B	PANK2	TOR1A	THAP1
ADCY5	SGCE	ATP1A3	EIF2AK2	ADAR1
ARX	HPRT1	ANO3	ATM	DNAJC6
MECP2	PLA2G6	SLC19A3	UBA5	22q11 dup
ACTB	AFG3L2	AIFM1	AIMP1	CACNA1G
CD40LD	DCAF7	FOXG1	GABRB2	GALC
GNB1	HPCA	IFIH1	L2HGDH	MECR
PDE10A	PDE2A	SCN2A	SLC6A3	SOX2
SUOX	TMEM240	TNPO2	TUBB4A	VPS16
WDR45				

Genetic diagnoses among all implanted cases submitted.
Source: DBSMatchMaker, December 2025. https://dbsmatchmaker.com/

- Clarification of the three-point response scale with explicit descriptors on the submission page
- Periodic e-mail status updates for cases submitted before DBS implantation, encouraging follow-up outcome reporting

These iterative changes improved usability, reinforced privacy protections, and supported more complete longitudinal data capture.

Emerging Patterns

Preliminary patterns from the aggregate data support current understanding of genetic subtype as a major determinant of DBS response in dystonia. GPi stimulation in *GNAO1*- and *KMT2B*-related cohorts yielded uniformly strong benefit ratings, whereas responses in *PANK2*-associated pantothenate kinase-associated neurodegeneration and *THAP1*-related dystonia appeared more variable. Although these observations are based on small, self-reported samples without standardized scales, they generate hypotheses regarding gene- and pathway-specific differences in DBS responsiveness that warrant formal prospective study.

Discussion

The first year of DBSMatchMaker demonstrates feasibility, global engagement, and clinician-perceived utility of a lightweight, web-based platform for DBS case matching and data sharing in rare movement disorders. The predominance of pediatric cases underscores the platform's relevance to early intervention in genetic dystonias, a population historically underrepresented in DBS trials and registries. Expanding participation from DBS programs treating adult patients with genetic movement disorders will be important to capture the full age spectrum of conditions such as *KMT2B*- and *ADCY5*-related disorders and to understand how disease stage influences outcomes.

Analogous to GeneMatcher in clinical genetics, DBSMatchMaker provides a scalable model for knowledge exchange in neuromodulation.[6] Its minimal mandatory data requirements and automated matching algorithm reduce logistical barriers that often limit multicenter collaboration. In addition to enabling rapid, case-by-case consultation, the platform allows aggregation of rare genotypes and phenotypes across institutions, creating cohorts that exceed the capacity of individual centers and that can inform practice in the absence of randomized trials.

To sustain and amplify this collaborative network, we have established two complementary initiatives: a monthly DBSMatchMaker newsletter, which shares anonymized case summaries, updates on ongoing multicenter collaborations, and technical refinements; and a monthly DBSClub seminar series, an open virtual forum where clinicians and researchers discuss submitted cases, review recent literature, and exchange best practices. Together, these initiatives extend DBSMatchMaker beyond a matching tool to an active learning community.

Several limitations of DBSMatchMaker and our analysis should be acknowledged. Outcomes are submitter reported and not uniformly supported by standardized rating scales (eg, Burke-Fahn-Marsden Dystonia Rating Scale) or centralized video review. Data completeness varies, and follow-up duration is not systematically captured. The current three-point response scale, while pragmatic, does not distinguish different domains of

benefit (motor vs. non-motor, quality of life, caregiver burden). Future iterations may incorporate optional structured outcome fields, semiautomated reminders for follow-up reporting, harmonized data elements with existing DBS registries, local field potential recordings, and device-specific programming data.

Conclusions

The early experience with DBSMatchMaker illustrates how community-driven digital platforms can accelerate knowledge generation and clinical decision-making in ultra-rare movement disorders. By lowering barriers to cross-center collaboration and creating a living repository of DBS experiences across genes, ages, and phenotypes, DBSMatchMaker has the potential to refine patient selection, inform target choice, and guide counseling in conditions where traditional trial infrastructure is difficult to establish. We invite clinicians worldwide to continue contributing cases and outcomes to strengthen the evidence base for DBS in rare genetic movement disorders.

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J.R.: 1A, 1B, 1C, 2A, 2B, 3A.
K.B.: 1A, 1B, 1C, 2A, 2C, 3B.
D.E.-F.: 1A, 1B, 1C, 2A, 2C, 3B.
K.Y.: 1A, 1B, 1C, 2A, 2C, 3B.

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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.

References

1. Zubair U, Agianda HAP, Yang K, et al. DBSMatchMaker: connecting clinicians globally for deep brain stimulation in rare diseases. Mov Disord 2025;40(4):765–767. https://doi.org/10.1002/mds.30131
2. Artusi CA, Dwivedi A, Romagnolo A, et al. Differential response to pallidal deep brain stimulation among monogenic dystonias: systematic review and meta-analysis. J Neurol Neurosurg Psychiatry 2020;91(4):426–433. https://doi.org/10.1136/jnnp-2019-322169
3. Rajan R, Garg K, Saini A, et al. GPi-DBS for KMT2B-associated dystonia: systematic review and meta-analysis. Mov Disord Clin Pract 2022;9(1):31–37. https://doi.org/10.1002/mdc3.13374
4. Sarva H, Rodriguez-Porcel F, Rivera F, et al. The role of genetics in the treatment of dystonia with deep brain stimulation: systematic review and meta-analysis. J Neurol Sci 2024;459:122970. https://doi.org/10.1016/j.jns.2024.122970
5. Duga V, Giossi R, Romito LM, et al. Long-term globus pallidus internus deep brain stimulation in pediatric non-degenerative dystonia: a cohort study and a meta-analysis. Mov Disord 2024;39(7):1131–1144. https://doi.org/10.1002/mds.29815
6. Sobreira N, Schiettecatte F, Valle D, Hamosh A. GeneMatcher: a matching tool for connecting investigators with an interest in the same gene. Hum Mutat 2015;36(10):928–930. https://doi.org/10.1002/humu.22844