Project FIND-OUT Referral Form

Thank you for referring a patient to Project FIND-OUT. Project FIND-OUT is designed to facilitate early and accurate genetic diagnosis of rare genetic neurodevelopmental disorders (RGND).

Please fax this form to (844)-452-3092 to begin the referral process or complete the online form located at: https://redcap.combinedbrain.org/surveys/?s=3PNN83NLPL3J994A

Section 1: Provider and Caregiver Information Contact Information

	Name	**Email**	**Phone**	**Specialty**
Provider				
Parents/Caregivers				N/A

Section 2: Patient Demographic Information

Patient Name	
Patient Date of Birth	
Patient Gender	□ Female □ Male □ Other
Patient Ethnicity/Race	□ Asian alone, non-Hispanic(including Middle Eastern, Pacific Islander, South East Asian) □ American Indian or Alaskan Native alone, non-Hispanic □ Black or African American alone, non-Hispanic □ Hispanic, Latino, or Spanish origin □ Native Hawaiian or Other Pacific Islander alone, non-Hispanic □ White alone, non-Hispanic □ Some other race/ethnicity alone □ Multiracial, non-Hispanic

Preferred Language	□ English □ Spanish □ Other, please specify:
Summarize the patient's chief complaint	
List any diagnoses the patient has received	
Provide any additional context (e.g., symptoms, abnormalities, specialist referrals, specific HPO terms that you would like to include) that would help inform the whole genome sequencing analysis	

Section 3: Project FIND-OUT Eligibility Criteria

The patient must meet 2 criteria to be eligible.

	Inclusion Criteria	**Definition**	**Check to Indicate If Patient Meets Criteria**
F	Feeding issues	Inability to suck, reflux, constipation, dysphagia	☐
I	Issues with movement/abnormal movements	Hyperkenetic movements (chorea, dystonia, myoclonus, tics, tremors, sterotypies), ataxia, tremulousness, torticollis	☐
N	NICU admission	Any NICU or ICU admission for any reason of any duration	☐
D	Developmental delay	Missed milestones in 2 or more domains such as communication, gross motor, fine motor, problem solving, or personal-social (can use any instrument to assess including ASQ or CDC), please specify which domains have missed milestones:	☐

O	Other (congenital malformations, atypical growth or specialist referral)	• Structural anomalies including dysmorphic features • Atypical growth in head circumference, weight, or length (<5 or > 95% on growth chart) • Referral to a specialist (Neurologist, Cardiologist, Gastroenterologist, Developmental Pediatrician, Audiologist, Ophthalmologist) or for PT/OT/ST or early intervention	☐
U	Unprovoked seizures	One or more unprovoked seizure	☐
T	Tone	Low muscle tone, floppy baby, head lag, diminished or absent tendon reflexes, hyperative or repeating tendon reflexes (clonus)	☐
	Exclusion Criteria		
	Has the patient received whole genome sequencing?		Yes ☐ No ☐

I confirm that the information is accurate, and the patient meets the Project FIND-OUT criteria:

- 3 – 12 months of age
- Meets at least two of the criteria in Section 3
- Has not received previous whole genome sequencing

_____ _____

Signature of Referrer Date

_____ _____

Name of Referrer Title

Return of Results

If you would prefer to have the genetics department in your practice or institution return results, please check the appropriate box below. If no box is checked, Project FIND-OUT's genetic counseling partner will return results.

□ The genetics department associated with my practice/institution will return results and will be able to return results within 1 week of receipt

□ Project FIND-OUT's genetic counseling partner will return results

Release of Healthcare Information

Please have your patient sign a Release of Healthcare Information allowing you to share information with Project FIND-OUT and allowing Project FIND-OUT to share the results of genetic testing with you. If the release is available at the time this form is submitted, please upload the release.

If you are unable to upload the release at the time the referral is submitted, you can return to this form and upload later, email the release to projectfindout@combinedbrain.org, or fax the release to (844)-452-3092.