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.

Section 1: Provider and Caregiver Information Contact Information

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

Section 2: Patient Demographic Information

Patient Name	
Patient Mailing Address	
Patient Date of Birth	
Patient Gender	□ Female □ Male □ Other
Patient Ethnicity/Race	□ Asian (including Middle Eastern or Pacific Islander) □ American Indian or Alaskan Native □ Black or African □ Latino or Hispanic □ White □ Other, including multi-ethnicity

Preferred Language	□ English □ Spanish □ Other
Summarize the patient's chief complaint	
List any diagnoses the patient has received	
Provide any additional context (e.g., symptoms, abnormalities, specialist referrals) that would help inform the whole genome sequencing analysis	

Section 3: Project FIND-OUT Eligibility Criteria

The patient must be between the ages of 3 and 12 months and live in the United States. 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 ☐

Section 4: Referral to Pediatric Neurology

Patients in Project FIND-OUT may need to be referred to a Pediatric Neurologist when the whole genome sequencing results are available.

Patient's Pediatric Neurology Referral Status	□ Pediatric Neurologist is already involved in the care of this patient □ Not yet referred, but will make referral

	□ Not yet referred and need assistance to make referral
Name of Pediatric Neurologist	
Email of Pediatric Neurologist	
Phone of Pediatric Neurologist	
Address of Pediatric Neurologist	
Date Referral Made	

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

- 3 – 12 months of age and lives in the United States
- 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