Boston Children's Hospital
Until every child is well™

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Brain Development and Genetics Clinic

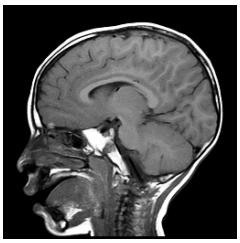
Thank you for your interest in our program. The Brain Development and Genetics (BrDG) clinic at Boston Children's Hospital is designed to provide a multidisciplinary approach to diagnosing, treating and counseling patients and families affected by developmental brain malformations. The diagnosis of a structural brain abnormality often leaves families with questions and looking for resources. Our clinic is intended to serve as a resource and bridge between the Neurology and Genetics care provided to families.

The BrDG Clinic combines specialists in neurology, genetics, genetic counseling and research to provide a more comprehensive approach to working with individuals diagnosed with brain malformations. Our team of specialists will review brain MRI imaging, diagnoses and test results, as well as discuss potential treatment options for neurological symptoms. Additionally, patients and families can discuss potential genetic testing recommendations and/or meet with a genetic counselor to learn about the inheritance of brain malformations. We can also provide information about participating in applicable research studies and resources for information and support.

For review of your/your child's diagnosis by our team and before being scheduled for an appointment in the BrDG clinic, we require the following information:

1. **Completed BrDG Clinic Medical and Family History Form** (this can be emailed, faxed or mailed)
2. **Medical records including:**
   - ☐ **Doctors notes and consultations (especially Neurology, Genetics or Metabolism clinics)**
   - ☐ **Brain imaging report and copy of MRI on CD/DVD**
   - ☐ Genetic and metabolic testing reports, as applicable
   - ☐ EEG reports and copy of EEG data on CD, if applicable and possible
   - ☐ Neuropsychiatric testing results, if applicable and possible

Medical records and imaging should be sent to:



Attn: Abbe Lai, BrDG Clinic Coordinator
Boston Children's Hospital
300 Longwood Ave, BCH3150
Boston, MA 02115

Phone: 617-919-4371
Fax: 617-730-0466
Email: geneticsBrDG@childrens.harvard.edu

After we receive and review the above information about you/your child, a member of our team will call you regarding a future appointment in our clinic. Thank you and we look forward to meeting you!

Please see the other side for more information about our team.

The Brain Development and Genetics Clinic

Christopher A. Walsh, MD, PhD *Founder and Principal Investigator*
Chief, Division of Genetics and Genomics, Boston Children's Hospital
Bullard Professor of Neurology and Pediatrics, Harvard Medical School

http://www.childrenshospital.org/centers-and-services/brain-development-and-genetics-clinic-program

http://www.walshlab.org/services

BrDG Clinic Providers

Christelle Moufawad El Achkar, MD
Pediatric Neurologist and Epileptologist
Attending in Neurology, Boston Children's Hospital

Abbe Lai, MS, CGC
Licensed Genetic Counselor
Division of Genetics and Genomics/Department of Neurology, Boston Children's Hospital

Ganesh Mochida, MD
Pediatric Neurologist
Staff Physician, Division of Genetics and Genomics, Boston Children's Hospital
Assistant Professor of Pediatrics, Harvard Medical School

Heather Olson, MD, MPH
Pediatric Neurologist and Epileptologist
Attending in Neurology, Boston Children's Hospital
Instructor in Neurology, Harvard Medical School

Annapurna Poduri, MD, MPH
Pediatric Neurologist and Epileptologist
Attending in Neurology, Boston Children's Hospital
Assistant Professor of Neurology, Harvard Medical School

Lance Rodan, MD
Geneticist
Attending Physician, Division of Genetics and Genomics/Department of Neurology, Boston Children's Hospital
Instructor in Pediatrics, Harvard Medical School

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Brain Development and Genetics Clinic

Medical/Family History Form

Please complete this form to the best of your ability and return it to us by fax, email or in an enclosed envelope.

Fax number: 617-730-0466

Email: geneticsBrDG@childrens.harvard.edu

Date Completed _____

Child's Name _____ Date of Birth _____

Parent #1 Name _____ Date of Birth _____

Parent #2 Name _____ Date of Birth _____

Home Address _____

Street City

_____

State/Country Zip

Home Phone _____ Cell Phone _____

Email _____

Languages spoken at home_____

Would you like a language interpreter present for your visit? ☐NO ☐YES

Child's condition or diagnoses_____

PRENATAL / BIRTH HISTORY

How many times has the patient's mother been pregnant? _____

Which of mother's pregnancies was this (1st, 2nd, etc)? _____

Was this pregnancy achieved through the use of any assisted reproductive technologies? ☐NO ☐YES

If yes, please indicate all that apply:

☐Artificial insemination ☐IVF ☐GIFT ☐ZIFT ☐ICSI

☐Assisted hatching ☐Blastocyst transfer ☐Egg donor ☐Surrogate

☐Sperm donor ☐Preimplantation genetic diagnosis (PGD)

How many biological children does the mother have? ____

Are all of these children currently living? ☐NO ☐YES

If no, please provide as much information as possible regarding any children who have passed away:

_____

_____

_____

Were there pregnancy losses/miscarriages before this pregnancy? ☐NO ☐YES How many?_____

Were there pregnancy losses/miscarriages after this pregnancy? ☐NO ☐YES How many?_____

Biological mother's age at delivery _____

Biological father's age at delivery _____

Please check No or Yes if the following occurred; if Yes please describe.

During pregnancy:

Illness	☐NO	☐YES	Describe:_____
Medication taken	☐NO	☐YES	Describe:_____
Bleeding	☐NO	☐YES	Describe:_____
Smoking	☐NO	☐YES	Describe:_____
Alcohol	☐NO	☐YES	Describe:_____
Prenatal testing	☐NO	☐YES	Type &Results:_____
Ultrasounds/Imaging	☐NO	☐YES	When &Results:_____

Length of pregnancy (in weeks):_____

Please describe any problems during pregnancy:_____

_____

_____

Labor and Delivery:

Induced	☐NO	☐YES	If yes, reason:_____
Lasted over 12 hours	☐NO	☐YES	
Cesarean section	☐NO	☐YES	If yes, reason:_____
Anesthesia	☐NO	☐YES	If yes, type: Spinal/Epidural/General (asleep)

Labor Complications: _____

Newborn Period:

Complications	☐NO	☐YES	If yes, describe:_____
Cried right away	☐NO	☐YES	

APGAR scores, if known: _____@ 1 minute; _____@ 5 minutes

Birth Measurements: Head circumference_____; Weight_____; Length_____

Went home after_____days in the hospital

Infancy:

Enjoyed cuddling	☐NO	☐YES
Fussy/Irritable	☐NO	☐YES
Less active than other babies	☐NO	☐YES
Floppy/low muscle tone	☐NO	☐YES
Poor feeding	☐NO	☐YES

Other information we should know:_____

_____

DEVELOPMENTAL HISTORY

If you can recall, please record the age (in months or years) at which your child reached the following developmental milestones. If you do not recall the specific age, please indicate your best guess at to whether this was early, normal or late. If your child has not yet achieved a milestone please indicate this. Please indicate if your child has ever lost a skill (regressed) after having previously acquired that skill.

Gross Motor Skills

Lifts head when prone	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Rolls front to back	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Rolls back to front	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Sits when placed	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Comes to a sit	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Crawls	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Stands w/o support	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Walks with assistance	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Walks independently	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____

Communication

Smiles	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Coos	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Babbles	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Says single words	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Speaks in phrases	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Speaks in sentences	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Speaks clearly	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Gestures (waves)	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Points for wants	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Understands commands	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____

Fine Motor Skills

Reaches for objects	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Holds objects	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Brings hands together	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Brings hands to mouth	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Uses pincer grasp	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Points with one finger	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____
Hand preference	☐ No	☐ Yes; *Age when acquired*_____	☐Lost Skill; *Age when lost*_____

Was the loss of any of these skills at the same time your child first developed seizures?

☐ No ☐ Yes ☐ Not applicable (no loss of skills)

List any services or therapies that your child receives & frequency:

Physical therapy: ☐ *Times per week* _____

Occupational therapy: ☐ *Times per week* _____

Speech therapy: ☐ *Times per week* _____

Other (please list type and frequency): _____

_____

_____

School Information

School Name/Location: _____

Grade in School: _____

Classroom type: ☐ Fully integrated ☐ Partially integrated ☐ Separate special education

Accommodations: _____

_____

_____

MEDICAL HISTORY

Imaging/MRI information:

What have you been told by your doctors about any structural brain abnormalities?

[ ] No structural brain abnormalities

[ ] Yes, structural brain abnormality present

If yes, please describe as you understand the findings

_____

_____

Please tell us if your child has ever had any of the following medical concerns:

Concerns involving...	**Yes**	**Describe** (ex. frequency, type, starting at what age)
Seizures		
Hearing		
Vision		
Headaches		
Allergies		
Heart		
Lungs		
Ear infections		
Blood (such as anemia)		
Kidney or bladder		
Stomach or bowel		
Bones		
Muscles		
Growth		
Serious head injury		
Serious injury		
Hospitalization		
Surgery		
Intellectual disability		
Developmental delay		
Behavior		
Mental health		
Sleep		
Learning disabilities		

EPILEPSY HISTORY (if applicable)

Age at time of 1st seizure: ☐less than 1 month ☐1 -3 months ☐4-6 months ☐7-12 months ☐> 1 year

Longest seizure free period: ☐< 1 week ☐1 week to 1 month ☐2-3 months ☐4-6 months ☐7-12 months ☐1-2 years ☐>2 years

Has your child ever had a very long seizure, lasting >15 minutes? ☐No ☐Yes

If yes, number of times this has happened_____

Please describe seizure types in detail below:

#	Seizure type	Description	Age of onset/ Age of resolution (if resolved)	Current frequency/ max. frequency
1				
2				
3				

4				

List any other health problems including genetic diagnoses: _____

_____

_____

MEDICATIONS

List any medications and doses that your child currently takes:

Name	Dose	Frequency (such as twice daily)	Side effects

List any other anti-seizure medications that your child has taken in the past:

Name	Max Dose if known	Side effects/Reason for Discontinuing

FAMILY HISTORY

Please complete this section to the best of your ability. If there are limitations in your knowledge of biological family members due to adoption, egg/sperm donation or other family circumstances please indicate this.

Parents

	Child's Biological Mother	Child's Biological Father
Current age		
Occupation		
Highest grade completed in school		
Medical problems		
Learning problems		
Mental health problems		
Previous MRI history,		
History of epilepsy, age of onset and seizure types if known, syndrome diagnosis? Cause? Febrile seizures?		

Because it can be important to know for genetic evaluations, are you child's parents related to each other by blood or do they share any blood relatives in common? ☐Yes ☐No

- Child's biological MOTHER's family's ethnic background/ancestry? (example: English, Nigerian, Russian, Jewish etc.)_____

_____

Your child's biological MOTHER has how many sisters? _____ How many brothers? _____

Please list mother's siblings' names, with the age of each person & how many children each person has. *Use back if necessary.*

First Name Full or Half Sibling Age # Daughters #Sons

_____

_____

_____

❖ Child's biological FATHER's family's ethnic background/ancestry? (example: English, Nigerian, Russian, Jewish etc.)_____

_____

Your child's biological FATHER has how many sisters? _____ How many brothers? _____

Please list father's siblings' names, with the age of each person & how many children each person has. *Use back if necessary.*

First Name	Full or Half Sibling	Age	# Daughters	#Sons

Siblings

Your CHILD has how many full sisters (same mother & same father)? _____Half sisters? _____

Your CHILD has how many full brothers (same mother & same father)? _____Half brothers? _____

Other Family History *Use back if necessary.*

- Below, please indicate the type of *medical, neurological, behavioral, mental health or learning problems* diagnosed in any relatives including siblings, cousins, aunts, uncles, grandparents (examples: **seizures, structural brain abnormalities, genetic diagnoses, cancer of any type, mental illness including depression/anxiety/bipolar disorder, vascular/heart disease, intellectual disability, learning disabilities, developmental delays, birth defects, autism, fertility problems or multiple miscarriages). Please indicate whether the relative is related to your child through the maternal or paternal side of the family.**
- In last column, please circle A for alive, D for deceased and indicate the current age, or age at death

RELATIONSHIP TO CHILD	FIRST NAME	TYPE OF PROBLEM	AGE DIAGNOSED	STATUS & AGE
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age
				A D Age

Please add any other information you would like us to know about your child and his/her family history:

CLINIC NOTES

If you would like the medical note from our meeting sent to other healthcare providers, please include their names and addresses below:

Health Care Provider	Name	Address	Fax
Primary Care/ Pediatrician			
Neurologist			
Other (please specify)			

INFORMATION NEEDS

We will discuss a number of topics during your visit. In order to help us meet your personal needs, please indicate if any of the following areas are of particular interest to you.

_____Review of diagnosis, including review of previous studies & results such as genetic tests, MRI, and/or EEG

_____Discussion of treatments

_____Genetic counseling, including discussion of genetics and inheritance and/or possible concerns for future pregnancies or other family members

_____Discussion of emotional aspects of caring for a child with special needs and/or sources of information and support

_____Discussion of potential enrollment into genetic research studies

Additional questions or concerns you would like to discuss: