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.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
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: __________________________________________________________

________________________________________________________
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:

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

<table>
<thead>
<tr>
<th>#</th>
<th>Seizure type</th>
<th>Description</th>
<th>Age of onset/ Age of resolution (if resolved)</th>
<th>Current frequency/ max. frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**List any other health problems including genetic diagnoses:**

______________________________

______________________________

______________________________
**MEDICATIONS**

List any medications and doses that your child currently takes:

<table>
<thead>
<tr>
<th>Name</th>
<th>Dose</th>
<th>Frequency (such as twice daily)</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Max Dose if known</th>
<th>Side effects/Reason for Discontinuing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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

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

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.

<table>
<thead>
<tr>
<th>First Name</th>
<th>Full or Half Sibling</th>
<th>Age</th>
<th># Daughters</th>
<th>#Sons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10
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.

<table>
<thead>
<tr>
<th>First Name</th>
<th>Full or Half Sibling</th>
<th>Age</th>
<th># Daughters</th>
<th>#Sons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**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

<table>
<thead>
<tr>
<th>RELATIONSHIP TO CHILD</th>
<th>FIRST NAME</th>
<th>TYPE OF PROBLEM</th>
<th>AGE DIAGNOSED</th>
<th>STATUS &amp; AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A  D Age</td>
<td></td>
</tr>
</tbody>
</table>

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

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

12
If you would like the medical note from our meeting sent to other healthcare providers, please include their names and addresses below:

<table>
<thead>
<tr>
<th>Health Care Provider</th>
<th>Name</th>
<th>Address</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care/ Pediatrician</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**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: ______________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________