

<b>Name</b>
HBKRH#:
DOB:
Health Card#:
Address:
Ph:
Email:
Parent/Guardian name

**Primary Diagnosis**

- **Rett Syndrome**  
*Rett Syndrome is a rare and unique developmental disorder that results from a genetic mutation at the time of conception (MECP2). Rett Syndrome is a clinical diagnosis, meaning that in some children the specific mutation has not been found, so the diagnosis is made based on the clinical presentation of Rett Syndrome. Not all children with Rett Syndrome present the same. Please refer to the developmental section to find out what \_\_\_\_ is able to do. \_\_\_\_ was diagnosed with Rett Syndrome in \_\_\_\_ (year). (Mutation: \_\_\_\_)*

**Secondary Diagnosis**

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**Allergies/Immunizations/Recent vital signs**

- Allergies, Immunizations ?up to date?
- Ht:            Wt:            \*HC:

**Current Medication**

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**Common Presenting Problems / Goals of Care:**

- Girls with Rett Syndrome are at risk for long QT syndrome. All drugs which may induce prolonged QT should be avoided.
- Resuscitation status if applicable

**Neonatal Summary**

**Equipment**

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**Summary of Systems**

Neurologic:

- **Seizures:** onset, frequency, management, follow up
- **EEG** (last one)
- **Brain Imaging**

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HEENT:

- **Hearing**
- **Vision**
- **Dental**

Cardio/Respiratory

- **Last ECG:**
- **Breathing abnormalities**

GI/Nutrition

- **Constipation**
- **GERD**
- **Gall bladder function**

GU/Endocrine

- **Puberty**

MSK & Bone Health

- **Scoliosis**
- **Spine X-ray:**
- **Bone Health:** dietary calcium, weight bearing, Vit D

Skin

- **Cold hands / feet**
- **Skin breakdown**

Sleep & Pain

- **Obstructive breathing**
- **Sleep habits**
- **Pain tolerance**

**Developmental Summary/Therapy**

Gross motor: \*apraxia, ambulation

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Fine motor: \*Stereotypies

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Adaptive:

Communication: \*eye gaze

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Behaviour: \*anxiety, impact on stereotypies

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**Community Services/Respite/School/Funding**

- **School:**
- **Respite:** Enhanced respite funding
- **Funding:** ACSD, Disability Tax Credit, Easter Seals Incontinence Grant
- **CCAC:** PSW or nursing
- **Recreation:**

**Social Summary**

**Care Providers**

Paediatrician / Family Doctor		•
Complex Care Rett Syndrome Pathway	Nancy Campbell, RPN Tessa Gresley-Jones, NP Dr. M. Carter	• Holland Bloorview Kids Rehab 150 Kilgour Road Toronto ON M4G 1R8 Ph: 416-425-6220 x3210 / 6453 Fax: 416-424-3837 E-mail: <a href="mailto:a.mullin@hollandbloorview.ca">a.mullin@hollandbloorview.ca</a> tgresleyjones@hollandbloorview.ca

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Neurology		•
Feeding Clinic	Dr. Berall Rebecca Perlin SLP	• Holland Bloorview Kids Rehab 150 Kilgour Road Toronto ON M4G 1R8 Ph: 416-425-6220 x3443
Nutrition Clinic	Dr. Telch Lorry Chen, RD	• Holland Bloorview Kids Rehab 150 Kilgour Road Toronto ON M4G 1R8 Ph: 416-425-6220 x6260
Orthopaedics		• Holland Bloorview Kids Rehab 150 Kilgour Road Toronto ON M4G 1R8 Ph: 416-425-6220
Therapists		•