# WHERE WILL THE APPOINTMENT BE?

We are a NSW state-wide service based in Newcastle and Sydney

Hunter Genetics – GOLD Service, WARATAH NSW 2298

&

GOLD Service Royal North Shore Hospital, ST LEONARDS NSW 2065

We also see families across NSW at outreach clinics and provide home-visits where necessary.

# WHAT SHOULD I BRING TO THE APPOINTMENT?

The genetic counsellor will advise you on what to bring with you, but typically this includes:

- The 'Blue Book' for children.
- Allied health, developmental clinic and school reports.
- Psychometric and autism assessment reports.
- Clinic letters and results from other doctors.
- Sometimes family pictures can also be useful to bring along.

#### **HOW TO CONTACT OUR TEAM:**

Hunter Genetics (Newcastle and any administrative questions):

**Phone:** (02) 4985-3100 opt 1

**Fax:** (02) 4985-3105

Email: HNELHD-GOLD@health.nsw.gov.au

Royal North Shore Hospital (Sydney based enquiries):

**Phone:** (02) 9463-1557

Email: HNELHD-GOLD@health.nsw.gov.au

#### PLEASE SEND REFERRALS TO:

Fax

(02) 4985-3105

**Email** 

HNELHD-GOLD@health.nsw.gov.au

**Postal Address** 

PO Box 84 WARATAH NSW 2298









# The NSW Genetics of Learning Disability (GOLD) Service

NSW State-Wide Clinical Genetics Service



### The NSW Genetics of Learning Disability (GOLD) Service



Our team is made up of:

- Clinical Geneticists (Genetic Doctors)
- Clinical Nurse Consultants / Genetic Counsellors
- · Administrative support staff

#### WHAT FAMILIES DO WE SEE?

- NSW families with more than one family member with intellectual disability, developmental delay or autism level 3
- Individuals and families with a confirmed genetic diagnosis of an inherited form of intellectual disability (including fragile X).

#### WHAT DOES THE GOLD SERVICE OFFER?

- A comprehensive clinical genetic service for families within NSW with inherited intellectual disability (including Fragile X syndrome).
- Testing other family members if the specific gene change responsible for intellectual disability within the family is known.
- Provision of current information on inherited forms of intellectual disability to families, health professionals and the community.
- Counselling regarding reproductive choices, and information about community resources and support groups.
- An Unresolved Intellectual Disability Research Program to identify genetic causes of inherited intellectual disability.
- Assistance for paediatricians ordering testing.

#### **HOW MUCH WILL IT COST?**

- There is no direct cost to you for the appointment or any recommended genetic testing.
- This service is funded by the NSW Ministry of Health. The cost of the consultation is covered by Medicare.

#### REFERRAL PROCESS

To arrange an appointment, a referral from a doctor (such as a GP, paediatrician or neurologist) is required.

#### Please direct referrals to:

Dr Tracy Dudding-Byth

Dr Mike Field or

Dr Caitlin Forwood

#### Please include with your referral, previous:

- Genetic test reports
- Clinical letters
- Allied Health reports

## WHAT HAPPENS AFTER THE REFERRAL?

- A genetic counsellor will call you to discuss the referral and obtain more information about your family history.
- An appointment will be arranged with a geneticist and genetic counsellor.
- At the appointment, the geneticist may ask to examine the referred individuals.
- · Genetic testing may be offered
- A blood sample or saliva/cheek swab may be collected.