

International LOWE (OCRL1) SYNDROME PATIENT Registry

To better understand the disease an international registry is being established. Confidentiality of personal information regarding incidence, genetics, clinical course and prognosis is provided to professionals and families. Your cooperation in registering and in helping to contribute information on Lowe individuals to the registry is greatly appreciated. Please print out and complete the form hand written or typed. Also please add any extra information, pictures or extra pages.

Registration of Lowe Subject

Name: _____

Title: _____

Specialty: _____

Address with Postcode and Country: _____

Telephone/ email: _____

The information I have provided may be summarized and communicated to other health care professionals if there is proper acknowledgement and the patient's identity remains confidential.

Signature _____ Date _____

Please Return completed signed form to:
The Lowe Subject Registrar, Lowe Syndrome Trust, 77 West Heath Road, London NW3 7TH

Today's Date: _____

Lowe Subjects Name: _____

Birth Date: _____

Address with Postcode and Country: _____

Age diagnosis was made: _____

By Whom:
Name: _____

Address: _____

Subject's personal physician or family doctor:

Name: _____

Address: _____

What was reason for ascertainment (what symptoms): _____

What is subject's weight: _____

Height: _____

Medical problems: _____

Signs or Symptoms	Yes/ Present	No/ Absent	Ages of Onse
Cataracts in both eyes	_____	_____	_____
Glucoma in one or both eyes	_____	_____	_____
Hypotomia (Floppyness)	_____	_____	_____
Development Delay - first walking?	_____	_____	_____
Development Delay - first words?	_____	_____	_____
Kidneys: Loss of nutrients	_____	_____	_____
Behaviour - hand-flapping	_____	_____	_____
Behaviour - obsessive	_____	_____	_____
Behaviour - self-harming	_____	_____	_____
Seizures/ epileptic fits	_____	_____	_____
Dental problems	_____	_____	_____
Arthritis/ joint pain/ loss of mobility	_____	_____	_____

What if any specific tests have been done:

Blood and urine?

DNA test?

Fibroblast test?

Family

Mothers Name: _____

Birth Date: _____

Father's Name: _____

Birth Date: _____

Brothers and sisters:

Name	Sex	Birth Date	Medical Problems
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

What school(s) have been attended. Please indicate if these are normal or special needs only. Please comment on the local social and education services support if any, for special educational needs.

Any family history of the disorder? If yes, what relatives?

Has subject been reported in medical literature? If so, where and when.

Other history / medicines / behaviors / observations / you may consider relevant.

Is the subject listed in the LSA membership or with any other medical support group?

Do you know everything that you need to know about the prescriptions? Use the following checklist to find out. Check off each piece of information by clicking in the check box. Then print the checklist and take to your doctor or pharmacist. Talk to your doctor or pharmacist to learn more about what you don't know.

For each prescription, do you know:

- The name (both brand name and generic name) of the medication?
- What effects to expect from the medication (for example, when it will start working and how it may make you feel)?
- How much medication to take?
- How often to take the dose and at what times of the day to take each dose?
- What food should the medication be taken with (with food versus without food)?
- For how long should the medication be taken?
- What to do if a dose is missed?
- What should be avoided while taking the medication (for instance, certain foods or drinks, or other medications)?
- If there are any restrictions on regular daily activities while taking the medication?
- What possible side effects can occur and what to do if they appear?
- How long to wait before reporting to your doctor that the medication is not improving the symptoms?
- How to properly store the medication?
- The expiration date of the medication?