

# **Clinical Nurse Specialist**

**Neuronal Ceroid Lipofuscinosis  
(NCL)**

**Battens Disease**

## **Job Description**

**Date: November 2014**

## **GOSH Profile**

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) is a national centre of excellence in the provision of specialist children's health care, currently delivering the widest range of specialist care of any children's hospital in the UK. It is the only specialist Biomedical Research Centre for paediatrics, the largest centre in the UK for children with heart or brain problems, and the largest centre in Europe for children with cancer. It works in partnership with the UCL Institute of Child Health (ICH), part of University College London, and together they form the largest paediatric research and teaching centre in the UK.

The hospital at Great Ormond Street is the only exclusively specialist children's hospital in the UK. It does not have an Accident and Emergency department and only accepts specialist referrals from other hospitals and community services. The population of children served by the hospital is characterised by those with multiple disabilities and/or health problems and rare and congenital (present at birth) conditions. Many children need the help of different specialist teams. Improvements in health care and diagnosis mean that many children have dramatically improved survival rates and more therapeutic options than was the case 10 years ago. Sadly though, many of the children cared for at GOSH still have life-threatening or life-limiting conditions.

The hospital receives over 220,000 patient visits (inpatient admissions or outpatient appointments) a year, and carries out approximately 18,800 operations each year.

The hospital has 355 patient beds, including 36 intensive care beds. Many of the children and young people on our wards require high dependency care or are classed as ward intensive care, requiring one-to-one nursing.

Around 3,800 full-time and part-time staff work at the hospital. The ICH has around 600 staff. Many senior staff have roles in both organisations.

The hospital has approximately 50 paediatric specialties, the widest range of any hospital in the UK, which uniquely enables it to diagnose and pioneer treatments for children with highly complex, rare or multiple conditions. It has 19 highly specialised national services.

## Job description

Job title	Clinical Nurse Specialist Battens Disease
Division/Directorate	Neurosciences
Band	7
Responsible to	Head of Nursing
Accountable to	Head of Nursing
Type of contract/tenure of post	3 years Fixed term
Hours per week	37.5
Location	Great Ormond Street Hospital for Children NHS Foundation Trust and occasional off site visits to other hospitals
Budgetary responsibility	n/a
Manages	none

## Scope of the role

As a senior nurse leader, the CNS is a key member of the speciality and Divisional nursing team with a responsibility to contribute to wider service delivery.

To enable the fulfilment of these requirements, all CNSs are expected to work clinically as part of a ward roster. This requirement is equivalent to two full 12.5 hour shifts per month based on full time employment (pro rata if part time) but may be subject to review according to service requirements.

To be familiar with and adopt the principles of the NHS Chief Nursing Officers vision for Compassion In practice (NHS Commissioning Board December 2012).

Contribute towards achieving the 'Great Ormond Street Hospital Vision for Nursing' (Jan 2013).

# Key working relationships

## Internal:

Doctors, nurses, Families and patients, psychosocial team, laboratory staff, theatres, other CNS teams, outpatients department.

## External:

Families, community services, referring hospitals, charities, Battens Disease Family Association.

# Main duties and responsibilities

- Take responsibility for a defined caseload of children and families incorporating a care co-ordination remit as agreed.
- Provide effective nursing leadership, expertise, advice and support to a team / department and ensure the provision of high quality care to children and families
- Act as a role model and highly competent practitioner
- Act as a designated resource to children and families, and other shared care professionals.
- Facilitate the development of the all staff within the team, including registered nurses, student nurses, doctors and others to support staff in delivering care based upon the most up to date evidence and best practice.
- Promote an innovative and progressive attitude to the continual improvement of patient care through research and evidence based practice
- Use measurable outcomes for safety, patient experience and service efficiency
- Have line management or supervisory responsibility for other members of the specialist nursing team as appropriate
- Develop and update clinical practice guidelines
- Work in accordance with the NMC Code of Professional Conduct, Trust policies and procedures and the Trust's Personal Responsibility Framework.

The post-holder will work within the Epilepsy Clinical Nurse Specialist team, with whom they will provide some elements of reciprocal cross cover for other specialist areas within the service for short leave periods between individuals in the CNS team to ensure continuity of a quality service for all patients

## Clinical

- Provide information, clinical advice and support to children and families within a defined caseload and act as a resource to other professionals involved in that child's care.

- Be a highly competent, knowledgeable and visible practitioner within the specialty ensuring the provision of high quality evidence based nursing care for the children and their families.
- Ensure that each child is assessed, and their care planned, implemented and evaluated in negotiation with the family and other staff caring for the child, and that this is accurately communicated and documented.
- Liaise with clinical, non-clinical and facilities staff in order to maintain a safe, friendly and welcoming environment for the children, families, visitors and staff.
- Act as an advocate for the child and family ensuring the provision of appropriate information and support services.
- Ensure that each child within the caseload has a named lead clinician and designated care co-ordinator to co-ordinate their care and ensure a smooth ongoing journey through effective discharge planning.
- Ensure effective communication between all members of the multidisciplinary team both internally and externally to the Trust, other hospital departments, relatives and visitors.
- Develop and maintain the clinical skills and knowledge necessary to provide clinically effective, evidence based patient care. This includes the expanded role and responsibilities of the nurse, within the Scope of Professional Practice. These new roles are developed following appropriate training.
- Be competent in the administration of medication under patient group directives or supplementary prescribing as relevant.
- Be fully aware of the uses, safety precautions and handling of equipment in the department.
- Develop and review policies and standards for the safe use of equipment and any new equipment introduced to the department as specialty / caseload appropriate.
- Provide support and counsel to families through hospital and in the community, with appropriate referral and liaison with other agencies.

### **Management and Leadership**

- Provide nursing leadership to develop, deliver and evaluate services.
- Support the effective management of patient activity throughout the care pathway with a focus on continuous quality improvement.
- Complete workload activity recording in line with Trust Policy
- Actively participate in an annual appraisal process including a review of the job plan and of the service, ensuring it meets the needs of the children, young people, their families, and the Departmental/Divisional/Trust objectives.
- Contribute to the service development plans as appropriate
- Assist the team in identifying potential cost reduction efficiency savings
- Act as a visible role model and foster an environment that enhances the patient family and staff experience
- Provide expert professional advice and support to colleagues
- Act as a clinical supervisor to other staff.

- As appropriate, manage the appraisal process for directly line-managed staff, ensuring that all staff have the opportunity to review their performance and develop a meaningful professional development plan.
- Ensure that all staff know where to access trust policies and clinical procedure guidelines and that staff adhere to these at all times
- In conjunction with managers and the Head of Nursing, ensure systems for the effective investigation and management of complaints and clinical incidents within the department are established, ensuring that lessons learned are shared within the unit, division and Trust as appropriate.
- Actively promote and engage with the patient quality (safety, effectiveness and experience) agenda and the transformation programme locally and across the Trust
- Lead on relevant elements of the corporate nursing and transformation agenda for the specialty and clinical unit and undertake relevant Trust wide projects in agreement with the line manager
- Initiate and develop audits of service delivery and implementation of findings to improve patient care.
- Act as an ambassador for the department and specialty both within and outside the Trust.
- Participate in events or publications that promote the Trust and children's nursing.
- Develop and maintain written information for families and external health professions.
- To offer education and support to all professionals caring for children and young people affected by Battens Disease.
- Participate and present at relevant conferences as appropriate.
- Develop a range of resources with colleagues to ensure support and education for families.

## **Educational**

- Ensure that all staff caring for children in the caseload have up to date clinical skills knowledge and competence
- Foster environments conducive to learning, inquiry, and research and to support the identification of the training and development needs of nursing staff / learners in the department.
- Support the Practice Educator with the planning, delivery and evaluation of training and education programmes.
- Play a lead role in educational development relevant to the specialty and caseload.
- Contribute to the provision of a validated supportive and challenging environment for student nurses in training, act as a supervisor and mentor to learners
- Participate as required with the delivery of appropriate orientations to the department for all new staff, learners and temporary staff.
- Act as a resource for students and junior multi-disciplinary colleagues, facilitating the development of junior staff
- Contribute to identification of learning needs and development of appropriate multi-professional programmes on a national basis

- Develop and evaluate teaching programmes for children/families, empowering them to manage their own condition and seek appropriate help and advice.
- Ensure that systems are in place to develop, assess and record competence of patients and carers to manage their own condition supported by strong governance arrangements
- Provide support and training to other professionals both within the Trust and in community/shared care settings to develop skills/knowledge to deliver appropriate specialist care to children and families within the caseload.
- Contribute to relevant university accredited education programmes both in the work place and in the university setting
- Participate in national / international events in order to further national / international knowledge and share best practice
- Have a leadership role in the development, production and evaluation of national and international clinical procedure / practice guidelines
- Maintain own professional development and mandatory training identifying learning needs in relation to specialist area of practice.

## **Research and Development**

- Initiate and lead improvement, audit and research studies relating to nursing and multidisciplinary care, within the specialist area of practice, presenting findings through presentations and writing for publication
- Actively promote research awareness and evidenced base care to ensure that all children are cared for in accordance with the latest evidence.
- Work within the research governance arrangements to support audit of practice and continual improvement - locally, nationally and internationally
- Develop and evaluate tools to audit practice within specialist area of practice
- As appropriate, to engage in research trials within specialist area of practice and publish results to increase the body of knowledge
- Keep up to date with emerging thinking / findings from other centres.
- Work with others to maintain service database, including ensuring data entry, retrieval and analysis and provide activity reports as requested

This job description is intended as an outline of the areas of activity and can be amended in the light of the changing needs of the service and will be reviewed as necessary in conjunction with the post-holder.

## **Directorate/Divisional Information**

### **1 Responsibilities of Clinical Nurse Specialist- Service Delivery**

#### **1:1 Local Responsibilities**

- Act as a central point of contact for all patients referred to the service throughout the UK with a diagnosis of Neuronal Ceroid Lipofuscinosis (NCL), Batten Disease
- Attend all clinics for NCL patients supporting families with the coordination of their care as appropriate
- The post holder would attend outpatients clinics for children with Batten's disease at both GOSH and the Evelina (assuming the Evelina were happy with this and once an honorary contract arranged) and where appropriate (and with the consent of the other trusts) attend other neuro-metabolic clinics that are held in the 2-3 hospitals in England who also provide care for this group of children, such as at Manchester Children's Hospital and Birmingham Children's Hospital.
- Outreach services - arrange and make home visits to achieve optimum support where appropriate
- Promote good liaison between regional and local services, health & social care to give optimum support to patients and families, attend review meetings
- Ensure patients have a smooth transition from child to adult services
- Be an active member of local Palliative care team/forum
- Work with local genetic counselling services to provide support to parents and extended family members

### **1:2 National responsibilities**

- Work collaboratively with other centres to promote best practice for NCL BD patients, improved education and teaching for relevant other professionals where required
- Act as the national professional advice resource for parents, professionals and other agencies relevant to NCL, Batten Disease
- Raise awareness of Batten disease & be an active member of relevant rare disease groups e.g. LSD collaborative
- Maintain up to date knowledge of, and where appropriate liaise with those engaged in NCL registry projects

### **1:3 Batten Disease Family Association (BDFA) Responsibilities**

- Work collaboratively with the BDFA Family Support Officer
- Support the BDFA in helping to organise, attending and speaking at the Annual Events e.g. AGM & family conference, networking events etc.
- Provide regular reports for the BDFA CEO, and/or present reports to the BDFA Board to assist in evaluating and developing the service
- Contribute to the relevant BDFA publications, website, information leaflets and promotional literature

### **1:4 International Responsibilities**

- Liaise with other worldwide support groups & nurse specialists
- Publish research and/or attend and address international conferences where appropriate to disseminate research findings & raise awareness of all the NCL's

## **2 Post Specifications**



## **2:1 Salary and Employment conditions**

- Standard Band 7 Post for fixed term of 3 years
- Sick Pay, awarding Trust to provide suitable cover for long-term sick leave, e.g. after 30 days continuous absence due to ill health, maternity Leave, awarding NHS trust to provide suitable cover
- Outreach budget agreed in advance & to be managed by post holder & line manager

## **2:2 Recruitment process**

- Awarding Trust to be responsible for advertising the agreed position with signposting/promotion by the BDFA
- Appointment Process: BDFA to be involved in review of candidates, interview process and final appointment

## **3 Service Evaluation**

- Post holder: review according to awarding NHS trusts guidelines and procedures.
- Report to be provided for BDFA CEO
- Service Evaluation: 6 month joint review process, NHS trust and BDFA CEO
- Implementation of changes, if required after joint review process, to be agreed by NHS trust and BDFA CEO

Great Ormond Street Hospital Foundation Trust is a dynamic organisation, therefore changes in the core duties and responsibilities of this role may be required from time to time. These guidelines do not constitute a term or condition of employment.

## **Personal Responsibilities**

We expect all our staff to share the values that are important to the Trust and behave in a way that reflect these. In keeping with the Trust's Personal Responsibility Framework and the Single Equality Scheme and Equality Policy, the post-holder will be expected at all times to take responsibility for their own actions, support multi-disciplinary and partnership working and develop a working environment of courtesy, fairness and mutual respect.

## **Conflict of Interest**

You are required to declare any involvement, either directly or indirectly, with any firm, company or organisation which has a contract with the Trust. Failure to do so may result in your application being rejected, or, if it is discovered after appointment that such information has been withheld, then this may lead to your dismissal.

## **Confidentiality**

On appointment you may be given access to confidential information which must only be disclosed to parties entitled to receive it. Information obtained during the course of employment should not be used for any purpose other than that intended. Unauthorised disclosure of information is a disciplinary offence.

### **Disclosure & Barring Service (Previously Criminal Records or 'CRB')**

Great Ormond Street Hospital is a regulated organisation and as such, you will have your criminal record checked. You will be asked at interview if you have any criminal convictions and a police check on the existence of a criminal record will be made if you are the preferred candidate for appointment to the post. GOSH reserves the right to withdraw any conditional offer of employment made on the basis of the outcome of your criminal records check.

### **Infection Prevention and Control**

You will be required to participate in performance audits with respect to Infection Prevention and Control and will be required to discuss this in your annual performance review. The following should also be noted:

- The post-holder should ensure a suitable and efficient assessment is made of the risks to both the recipient and provider of care in respect of infection prevention and control issues.
- The post-holder is required to make him/herself aware of and comply with national and local infection prevention and control guidance.
- Where children are in their care the post-holder must investigate any health care-associated infection.
- The post-holder should audit performance with respect to infection prevention and control (in a way appropriate to their service) and discuss this in their annual appraisal.

### **Health and Safety**

All staff have a general accountability for ensuring, so far as is reasonably practicable, the health, safety and welfare of Trust employees. The following should also be noted:

- Each employee is required to take reasonable care for his or her own acts or omissions and the effect that these may have upon the safety of themselves or any other person.
- Every employee must use safety equipment or clothing in a proper manner and for the purpose intended.
- Any employee who intentionally or recklessly misuses anything supplied in the interests of health and safety will be subject to disciplinary procedures.
- Every employee must work in accordance with any health and safety procedures, instructions or training that has been given.
- No employee may undertake any task for which they have not been authorised and for which they are not adequately trained.
- Every employee is required to bring to the attention of a responsible person any perceived shortcoming in the Trust's safety arrangements or any defects in work equipment.

- All employees are under a duty to familiarise themselves with the Trust's Health and Safety Policies.

### **Risk Management**

You will be required to ensure that you implement systems and procedures at a local level to fulfill the requirements of the organisations Risk Management Strategy including local management and resolution of complaints and concerns, management of SUIs/incidents and near misses. Your specific responsibility for risk management will be clarified to you by your manager at your local induction.

### **Emergency Planning**

In accordance with the organisations responsibilities under the Civil Contingencies Act 2004, you may be required to undertake alternative duties as is reasonable directed at alternative locations in the event of and for the duration of a significant internal incident, major incident or flu pandemic.

### **Human Rights**

You are required to comply with the regulations of the Human Rights Act 1998 during the course of your employment.

### **Sustainable Development**

You will be required to demonstrate a personal commitment to the Trust's Sustainable Development Plan and to take personal responsibility for carrying-out your work duties in a way which is compliant with this Plan.

## **PERSON SPECIFICATION**

**Post: Clinical Nurse Specialist**

**Band: 7**

**Dept/ward: Neurosciences**

**Division/Directorate: Neurosciences**

<b>REQUIREMENTS</b>	<b>CRITERIA</b>	<b>ESSENTIAL/ DESIRABLE</b>	<b>HOW ASSESSED? *</b>
1. Education/ Qualifications/ Training	On the relevant part of the NMC register i.e. Children's registered	E	AF
	Evidence of ongoing, dynamic continuing professional development within the specialty, linked to demonstrable clinical competencies	E	AF
	Assessing and mentoring qualification	E	AF
	Possession of a relevant honours degree	E	AF
	Recognized teaching qualification	D	AF

2. Skills/Abilities	Excellent relevant clinical skills	E	IV
	Expert specialist skills and abilities for the post	E	IV
	Excellent managerial, leadership and organizational skills:	E	IV
	Able to motivate and develop a multi-professional team	E	IV
	Able to problem solve and initiate change	E	IV
	Negotiating skills	E	IV
	Self-discipline and good time management to support periods of lone working.	E	IV
	Interviewing skills	E	IV
	Appraisal skills	E	IV
	Ability to delegate and prioritise	E	IV
	Excellent verbal and written communication and listening skills	E	IV
	Excellent teaching, training and preceptorship skills	E	IV
	Able to work across professional team and organizational boundaries	E	IV
	Administration of IV drugs, as appropriate	E	IV
	Phlebotomy and canulation skills, as appropriate	E	IV
Administering medication under patient group directives or supplementary prescribing as appropriate.	E	AF	
Computer literate (word processing, PowerPoint presentation)	E	AF	
3. Experience	Sufficient experience at band 6 level or equivalent, including within relevant clinical environment	E	AF/IV
	Experience of leading and managing a team.	E	AF/IV
	Experience of working as a CNS	D	AF/IV
	Previous experience of research and audit	E	AF/IV
	Previous experience of change management	E	AF/IV

	and problem solving		
	Experience of handling clinical incidents and complaints	E	IV
	Demonstrates Compassion In Practice	E	AF/IV
4. Knowledge	Expert knowledge relevant to the specialty/field or practice	E	IV
	Understanding of professional and current issues in children's nursing and healthcare, e.g. Laming Report, Francis report, CNO's vision for Compassion In practice	E	IV
	Detailed understanding of audit and research methodologies	E	IV
	Understanding of resource management, health and safety, clinical risk and quality issues	E	IV
	Child protection procedures	E	AF/IV
	Handling clinical incidents and complaints	E	AF/IV
5. Other Requirements	Ability to initiate, manage and sustain change	E	IV
	Good attendance record	E	IV
	A flexible approach to work	E	IV
	Evidence of fulfilling PREP	E	IV
	Ability to work as an integral part of the multidisciplinary team	E	IV
	Ability to deal with conflict situations	E	IV
	Car driver (as appropriate)	E	IV
	Be flexible with hours	E	IV

\* Key:           AF = Application Form  
                      I = Interview  
                      T = Test

