

Job Description and Person Specification

Clinical Care Coordinator - Rare Bone Disease

Permanent Vacancy

Reference: HR25E222

Closing Date for Applications: Wednesday, September 17th 2025 In Person Interview Date: To Be Confirmed

> HR Business Services, St Vincent's University Hospital, Elm Park, Dublin 4.

Contact: 01 221 6062 or recruitment@svuh.ie







Accountability and Working Relationships

Title: Clinical Care Coordinator – Rare Bone Disease

Reports to: ERN Clinical Lead/Co Lead on the rare disease programmer of work and to Director of

Nursing/HSCP Manager as appropriate

Role Summary: This role is attached to the Rare Bone Disease Service at SVUH which is the lead adult centre for the European Reference Network for Rare Bone Disease (ERN BOND).

The successful candidate will attend the monthly Orphanet Bone clinic and provide phone clinic and phone advice services between in-person visits. They will maintain the Rare Bones email account. They will co-ordinate testing – eg metabolic bone laboratory, clinical genomics, radiology, pulmonary function, audiology – and treatments – eg infusion suite or liaison with home nursing service providers, community allied health professionals; ensuring prescription renewal and pharmacy co-ordination. They will attend rheumatology MDT for local case discussion and co-ordinate Case Patient Management System (CPMS) EU discussions.

They will assist in maintenance of the Core and eREC EURREB registries and the annual Irish EU activity return. They will enable transition from paediatric to adult services, including patient and family support. They will support clinical trial set up, enrolment and conduct in partnership with trial nursing staff. They will contribute to local protocol development and review.

They will contribute to EU guidelines and ERN group activity and integrate best practice into local care plans/pathways. They will work with referring centres to ensure enrolment of patients nationally into EURREB, and support patients accessing care locally between SVUH visits.

They will support departmental patient information meetings and liaise with patient societies e.g. Brittle Bone Society, XLH Alliance, EURORDIS.

Key Duties and Responsibilities

- Comply with own professional body as appropriate.
- To be aware of own needs regarding supervision and professional development and to work actively towards meeting these.
- To work in close conjunction with all members of the clinical team to ensure that a cohesive and effective service is provided.
- Ensure patient confidentiality is respected and the dignity of the patient is assured and maintained at all times having regard to the philosophy and ethical code of the Hospital.
- Have a good insight into the elements needed to support effective and innovative ways of changing clinical methods of working within established practices.
- Establish the role and authority of the post. Act as a role model demonstrating high standards of clinical practice and provide clinical leadership in the specialist area.
- Be aware of budgetary constraints and cost implications
- Contribute to the assessment, planning, implementation and evaluation of quality care to patients, in order to increase health gain and quality of life
- Where necessary, make recommendations to improve service.
- Provide expertise for patients using the service which optimises quality and continuity of care between primary and secondary care.
- Participate in MDT discussions regarding patient treatment, admission priorities and new policies, evaluating clinical problems, co-ordinate investigations, therapy and patient follow up in order to

- increase health gain and quality of life for patients; and to coordinate Clinical Patient Management System (CPMS) discussions at European level
- Regular audit of service with patient questionnaire/feedback. Use this as a springboard to assess future service needs/patient service changes.
- Provide specialist support services for patients such as a telephone advice service/specialist drop in/ outpatients' service.
- To ensure hospital policies and procedures and National Guidelines pertaining to the Services are adhered to. To provide a first line contact for all staff with queries relating to the speciality.
- Maintain awareness of current developments in the treatment and management of these patients. Act as an effective role model for other staff, administering the service through evidence based practice and patient care initiatives, aimed at improving quality of care.
- Contribute to the planning and organisation of out-patient clinics with the multidisciplinary team.
- Provide a safe environment for patients/ other staff/ self, with due regard to Health, Safety and Risk Management issues.
- Act as a patient advocate within the multidisciplinary team.
- Communicate, negotiate and represent patient's values and decisions in collaboration with other professionals and family members.
- Identify the educational needs of staff and students and liaise with training and academic departments in the delivery of an ongoing programme of education both in the hospital and in the community.
- Provide information and update sessions at ward and departmental level to aid staff and patients in their knowledge and understanding of the speciality
- Be actively involved in the teaching of new staff and post graduate students, in conjunction with relevant personnel.
- Demonstrate responsibility for professional growth by ensuring personal and educational development within an agreed personal development plan.
- Review, evaluate and improve the educational programmes regularly to optimise patient services and care delivery.
- Membership and participation in appropriate courses, conferences and professional organisations, to ensure personal continuing education and professional development using national and local guidelines.
- To initiate and take part in research relevant to the speciality, aimed at optimising patient care/ services. To maintain awareness of current developments in the management of patients receiving treatment and demonstrate knowledge of clinical trials.
- Where clinical trials take place, actively contribute to their effectiveness particularly in relation to recruitment, informed consent and advocacy.
- Assist in audit and evaluation in order to monitor the effectiveness of current therapeutic regimes and to improve health outcomes.
- Facilitate, develop and monitor quality initiatives in line with local and national requirements or guidelines.
- Assist department heads in the collection and correlation of statistical information and data in order to audit the service and aid the planning of future patients/service improvements/ initiatives.
- To attend regular meetings to review service performance, hospital and business plan.
- Act as an effective role model for other staff, administrating the service through evidence based practice and patient care initiatives, aimed at improving quality of care.
- Assist the Consultant in the production of an Annual Report, including the annual EU return.
- Develop and maintain strong interpersonal skills to communicate efficiently and effectively with colleagues, patients and their families.
- Establish clear referral patterns to, and lines of communication with medical staff, ward staff and relevant professionals (e.g. General Practitioners, Public Health Nurses, Practice Nurses) and act as an expert practitioner aimed at improving patient outcomes.

• Ensure, in co-operation with the Lead Clinician, the most effective and efficient use of developments in information technology for both patient care and administrative support in a manner which integrates well with systems throughout the organisation, including advances in electronic healthcare records, Orphacoding and the European Health Dataspace.

Section 3: Competencies

Clinical Focus

- Identifies health promotion priorities in the area of specialist practice.
- Implements health promotion strategies for patient/client groups in accordance with public health agenda.
- Contribute to rare disease clinical trial coordination
- Assist in the consenting of patients and families for rare disease registries
- Support the Clinical Lead and Data Manager in the annual ERN audit process
- Support the Clinical Lead and Data Manager in the ERN 5 yearly evaluation process and relevant documentation

Patient/Client Advocacy

- Enables patients/clients, families and communities to participate in decisions about their health needs.
- Articulates and represents patient/client interests in collaboration with the interdisciplinary team.
- Implements changes in healthcare service in response to patient/client need and service demand.
- Co-ordinate patient care plans across cross-sectoral specialties and disciplines
- Establish and support the development of agreed rare disease referral pathways and processes across both acute and community-based settings
- Provide specialist support, information and liaison services to patients/families and carers, acting as first point of contact
- Assist in the effective transition from paediatric services to adult services as required
- Participate in the development and implementation of rare bone disease care pathways, in collaboration with patient organisations and multidisciplinary stakeholders and the National Rare Diseases Office (as required)
- Attend planning, progress and review multidisciplinary team meetings, including establishing a national virtual MDT platform to include all BOND-Ireland sites
- Administer a rare disease database to facilitate case management, coordination and data collection, where required

Audit and Research

- Identifies, critically analyses, disseminates and integrates relevant evidence into the area of specialist practice.
- Initiates, participates in and evaluates audit, including return of annual data to EU.
- Uses the outcomes of audit to improve service provision.
- Contributes to service planning and budgetary processes through use of audit data and specialist knowledge.

Consultancy

- Provides leadership in clinical practice and acts as a resource and role model for specialist practice.
- Generates and contributes to the development of clinical standards and guidelines.

Rare Disease Service Quality and Improvement

- Commit to adopting a patient partnership approach to ensure patients and families with lived experience of rare diseases inform service developments
- Develop relevant SOPs and guidelines as applicable to support the effective operation of the service
- Develop and administer KPIs, outcome measures and a process for monitoring quality of care and measuring service impact and performance
- Participate in clinical risk management and identify areas for improvement where required

Section 4: Training and Education

- In association with staff members, provide support in the development and implementation of the orientation programme for new staff.
- Attend regular study days and conferences to maintain current knowledge.
- Work closely with Practice Development Co-ordinator, Clinical Placement Co-ordinators, and the staff in the Nurse Education Centre in leading and supporting relevant education and training programmes.
- Educates patients/clients, families and communities in relation to their healthcare needs in the specialist area of practice.
- Identifies own Continuing Professional Development (CPD) needs and engages accordingly.
- Contribute to the education and awareness of rare immune diseases and the available treatments and resources for healthcare professionals, patients, families and relevant external agencies
- Develop materials and mechanisms for educating referrers and community-based teams on matters relating to RD presentation, assessment and management

The above Job Description is not intended to be a comprehensive list of all duties involved and consequently, the post holder may be required to perform other duties as appropriate to the post which may be assigned to him/her from time to time and to contribute to the development of the post while in office. This document must be regarded as an outline of the major areas of accountability at the present time, which will be reviewed and assessed on an on-going basis.

The Hospital Structure is currently under review and therefore, reporting relationships may change.

Informal Enquiries or Role Specific Enquiries:

Mr Andrew Stoutt; HR Executive, SVUH; Email; Andrewstoutt@svhg.ie or Tel; 01 221 6034

Person Specification

Factors	Essential	Desirable
Qualifications	Candidates must at the latest date of application:	Recognised postgraduate qualification relevant to role
	Be a Health Care professional with a recognised professional qualification in Therapy or Nursing grade AND Be entitled to be so registered on an appropriate professional register e.g. CORU, NMBI or other appropriate	
	clinical/professional register OR Be eligible for membership https://www.coru.ie/ (https://www.nmbi.ie/) OR	
	Health and social care therapy applicants who satisfy the conditions set out in Section 91 of the Health and Social Care Professionals Act 2005, (see note 1 below*), must submit proof of application for registration with the Registration Board at CORU. The acceptable proof is	
	correspondence from the Health and Social care Registration Board at CORU confirming their application for registration as a Section 91 applicant.	
	Annual Registration (i) On appointment, practitioners must maintain annual registration on their professional register maintained by CORU or NMBI. AND	
	(ii) Practitioners must confirm annual registration with CORU or NMBI to the HSE by way of the annual Patient Safety Assurance Certificate (PSAC)	
Experience	All candidates must have 5 years full time (or equivalent) years post qualification clinical experience and in a post within the healthcare service, which demonstrates evidence of a management/ leadership role in a multidisciplinary/interdisciplinary team.	Demonstrated experience of working in partnership with clinicians, patients and caregivers to improve care outcomes
	All candidates must have the requisite clinical, managerial and administrative knowledge and ability (including a high	Experience delivering quality improvement in a healthcare environment

	standard of suitability and management ability) for the proper discharge of the responsibilities and duties of this role.	Experience working in and leading a team in an acute hospital environment Experience with Microsoft Office Suite, including Outlook and Excel Experience working in a rare disease or specialist care setting Demonstrated achievement in the areas of clinical audit, quality improvement initiatives, practice development, teaching and research Previous management experience
Professional	All candidates must demonstrate evidence	
Development and Practice	of continuing professional development in the form of post-graduate qualifications or relevant courses. AND All candidates must demonstrate achievement in the areas of clinical audit, quality improvement initiatives, practice development, teaching and research AND All candidates must demonstrate experience of interacting with multiple internal and external stakeholders as relevant to the role.	
Core Competencies	Planning & Managing Resources	
Competencies	Decision Making & Judging Situations	
	Setting Standards & Ensuring Quality	
	Influencing People and Events	
	Managing Individual Performance	
	Being the communication channel	
	Creating Team Spirit	
	Being a Leader & Role Model	
	Embracing the Change & Service Development	

Health	Candidates for and any person holding the office must be fully competent and capable of undertaking the duties attached to the office and be in a state of health such as would indicate a reasonable prospect of ability to render regular and efficient service.	
Character	Candidates for and any person holding the office must be of good character.	

Note 1*:

Section 91 candidates are individuals who qualified before 30 September 2016 and Have been engaged in the practice of the profession in the Republic of Ireland for a minimum of 2 years fulltime (or an aggregate of 2 years fulltime), between 30th September 2011 and 30th September 2016 are considered to be Section 91 applicants under the Health and Social Care Professionals Act 2005.

Particulars of Office:

The appointment is: Whole-time, Permanent and Pensionable.

Panel: A panel may be formed to fill upcoming permanent, temporary, whole and part-time vacancies over the next 6 months.

Annual Salary: Clinical Coordinator (3070) as at 01/08/2025, pro rata

1	2	3	4	5	6	7	8	9
€70,698	€72,062	€73,464	€74,858	€76,251	€77,718	€79,263	€80,804	€82,040

These particulars are subject to change in line with overall public pay policy.

<u>Candidates should expect to be appointed on the minimum of the salary range and in accordance with the Department of Finance guidelines.</u>

Probationary Period: The appointee shall hold office for a probationary period of six months – The Hospital's Probation and Induction policy will apply.

Pension Scheme: The candidate will be entered into one of the Hospital Superannuation Schemes.

Working Hours: Nursing or HSCP conditions will apply depending on the registered profession of the successful applicant(s) You will be required to work the agreed roster / on call arrangements advised to you by your line manager. Your contracted hours of work are liable to change between the hours of 8am – 8pm over seven days to meet the requirements for the extended day services in accordance with the terms of the Framework Agreement. (Reference HSE HR Circular 003/2009). Flexibility on hours of attendance in response to service needs will be a requirement.

Annual leave entitlement: Nursing or HSCP conditions will apply depending on the registered profession of the successful applicant(s). Annual leave accrued must be taken within the duration of the contract or calendar year and as agreed between the candidate and the Head of Department.

Additional Information

Confidentiality:

During the course of employment staff may have access to or hear information concerning the medical or personal affairs of patients, students, staff and / or other health service business. Such records and information are strictly confidential and unless acting on the instruction of an authorised officer, such information must not be divulged or discussed except in the performance of normal duty. In addition, records must never be left in such a manner that unauthorised persons can obtain access to them and must be kept in safe custody when no longer required.

Hygiene:

During the course of employment staff members are required to ensure that the hospital's hygiene and infection control policies are adhered to at all times. All employees have responsibility to prevent transmission of infection by adhering to and implementing optimal hand hygiene and adhering to the Hospital's Hygiene processes. Hygiene is a fundamental component of St Vincent's University Hospital's quality system to ensure the safety and well-being of its patients and staff and plays a role in the prevention and control of healthcare associated infection.

Policies / Legislation:

All Hospital policies and procedures form an integral part an employment contract and may be subject to update and revision, from time to time, in consultation with union representatives as appropriate. Employees are required to comply with all hospital policies, procedures (e.g. Dignity at Work, Trust in Care, Computer Usage Policy) and the Hospital's ethical codes of practice.

Employees are required to abide by the hospital's code of behaviour and the code of practice as defined by their relevant professional body.

Protected Disclosure Policy:

See link below for more information on our Protected Disclosure Policy as per the Protected Disclosure (Amendment) Act 2022;

Protected Disclosures - St. Vincent's University Hospital (stvincents.ie)

Please note the following:

- The Hospital Board is not responsible for loss or theft of personal belongings
- Fire orders must be observed and staff must attend the fire lectures periodically
- All accidents within the department must be reported immediately.
- In line with the Safety, Health and Welfare at Work Act (2005), smoking within the Hospital Building is not permitted.
- All staff are advised to avail of Hepatitis B Vaccination with Occupational health
- The use of personal mobile phones is prohibited.
- St. Vincent's University Hospital buildings and grounds are **smoke-free**.

Application Process: St. Vincent's University Hospital is an equal opportunities employer and is committed to promoting an environment free from discrimination in accordance with the Employment Equality Acts 1998 and 2004. The Hospital values diversity and recognises the benefits of having a workforce that reflects the community we serve. We are committed to equality of access to positions within the Hospital. All recruitment activity and documentation will encourage applications from all potential candidates without discrimination.

Interested candidates should apply for vacancies of interest by visiting the Hospital Careers pages: http://www.stvincents.ie/Home/Careers.html

- Note the closing date(s) for the submission of electronic applications are specified on the list of vacancies. St. Vincent's University Hospital are not able to accept late applications.
- It is the applicant's responsibility to ensure that they apply well in advance of the closing date.
- Any applications which are still in progress but have not been submitted after the closing date will not be registered.
- Applications for St. Vincent's University Hospital job vacancies will only be accepted through our Career website.
- St. Vincent's University Hospital may only take into account technical issues raised by an applicant if advised to our Human Resources Department prior to the advertised closing date.

Non-European Economic Area Applicants: While St. Vincent's University Hospital is an equal opportunities employer, in line with current Department of Jobs, Enterprise and Innovation Employment Permit requirements, applications from non-European Economic Area (EEA) will only be considered in the event that an EEA citizen cannot be found to fill the vacancy. Please note that if you are a NON-EEA applicant and are unable to supply documents (listed on www.djei.ie), you are not entitled to participate in this recruitment competition. This is in accordance with the EU Community Preference Rule. Further information is available at www.djei.ie.

Former Public Service employees: Eligibility to compete may be affected where applicants were formerly employed by the Irish Public Service and previously availed of an Irish Public Service Scheme including:

- Incentivised Scheme for Early Retirement (ISER)
- Department of Health and Children Circular (7/2010)
- Collective Agreement: Redundancy Payments to Public Servants

Applicants should ensure that they are not precluded from re-engagement in the Irish Public Service under the terms of such Schemes. This is a non-exhaustive list and any queries should be directed to an applicant's former Irish Public Service Employer in the first instance.

Persons in receipt of a pension from specified Superannuation Schemes: Former Health Service and Public Sector Employees must adhere to the relevant prohibition of re-employment provisions where they have previously availed of a Public Service Voluntary Early Retirement or III Health Retirement Pension from any of the following Pension schemes:

- Local Government Superannuation Scheme (LGSS)
- Health Service Executive Employee Superannuation Scheme
- Voluntary Hospitals Superannuation Scheme (VHSS Officers/Non Officers)
- Nominated Health Agencies Superannuation Scheme (NHASS)
- Other Public Service Superannuation Scheme

Among the Voluntary Early Retirement Schemes referred to above are the following:

- Incentivised Scheme of Early Retirement (ISER)
- Voluntary Early Retirement Scheme 2010 (VER)

Prospective candidates must satisfy themselves as to their eligibility to be employed applying / competing for posts to be filled through this recruitment campaign.

Abatement of Pension (Section 52 of Public Service Pensions Act 2012): Where a person who is in receipt of a Public Service Pension (e.g. retired on voluntary age grounds) is subsequently appointed to another Public Service post, the Abatement of Pension Regulations apply. This means that in a situation where the total of a person's pension combined with their salary from their new post, exceeds the uprated (current) salary of the position from which they retired, his/her pension is reduced by any such excess amount. This provision applies irrespective of whether the relevant pension was accrued in the same Pension Scheme which applies to the new appointment, or in another Public Service Pension Scheme.

Shortlisting: Shortlisting will be carried out on the basis of information supplied on your curriculum vitae. The criteria for shortlisting are based on the requirements of the post as outlined in the Person Specification. Failure to include information regarding these requirements on your CV may result in you not being called forward to the next state of the recruitment process.

All overseas qualifications must be validated. No candidate can work in the Hospital without validated qualifications. If professional registration is also a requirement, candidates must provide documentation of same.

Canvassing will automatically disqualify.

Please note that you will be contacted mainly by mobile phone and email. It is important that your mobile phone number, postal address and email address are correct. It is your responsibility to ensure that you have access to your mobile voice mails and emails. We recommend that you use an email address that you have regular access to.

Competency based interviews follow the shortlisting stage of the recruitment process. Credit is awarded by the interview panel to candidates who demonstrate at interview that they possess the experience, competencies and skills listed in the person specification. Candidates will normally be given at least one weeks' notice of interview. All interviews are held in person unless it is specifically noted otherwise in the Job Description. No subsequent or alternative dates to dates given will be offered to candidates. All posts are located in St. Vincent's University Hospital, Elm Park, Dublin 4 unless it is specifically noted otherwise in the Job Description.

Disability: Please let us know if you need any special assistance at interview, e.g. if you have difficulty in moving up or down stairs or have hearing or speech difficulties.

Candidates are notified of the result of their interview at the earliest possible date after the interview. The recommendation of the interview panel does not constitute a job offer. The process continues after the interview and includes clearance checks such as references, Garda clearance, overseas police clearance (if applicable)*, occupational health clearance, validation of qualifications and experience. A job offer is made pending satisfactory clearances. SVUH reserves the right to remove candidates from specific recruitment panels and retract job offers if satisfactory clearances cannot be obtained or are deemed unsatisfactory.

* If you lived in any country for 6 months or more from the date of your 16th birthday other than the Republic of Ireland or Northern Ireland you will be required to provide security clearance for each jurisdiction in which you have resided. Your security clearance must be dated AFTER you left that country and cover the entire period of your residence. Seeking security clearances from other countries are the responsibility of the candidate. It is a process which can take an amount of time. Therefore we would strongly advise that you commence seeking international security clearances now.

For some recruitment competitions a panel of successful candidates may be formed as a result of the interviews. Candidates who obtain a place on the panel may, (within the life of the panel), be considered for subsequent approved vacancies. Candidates are placed on a panel in order of merit. A panel is typically live for 6 months.

It is normal procedure that candidates be placed on the first point of the relevant salary scale in accordance with the Department of Finance guidelines.

Declaration: Please read your application carefully and check for any errors or omissions. False declaration or omission in support of your application will disqualify you from appointment.

This document must be regarded as an outline of the major areas of accountability at the present time, which will be reviewed and assessed on an on-going basis.

September 2025