

The McKenna Scholarship 2021 – Terms and Conditions

THE BACKGROUND TO THE MCKENNA SCHOLARSHIP

Children's Palliative Care in Ireland

There are more than 3,840 children living in Ireland with life-limiting conditions; approximately 1,900 of whom have palliative care needs; with up to 720 of these children and their families require specialised hospice care as the child's health is classified as unstable, deteriorating or at end-of-life. More recent UK research indicates that the incidence of children with life-limiting conditions could be double these estimates.

Children's Palliative Care is a relatively new specialty in pediatric healthcare, it is widely recognized that there is a dearth of research in this area. [Goldman et al 2012ⁱ, Downing 2015ⁱⁱ, Quinn et alⁱⁱⁱ]. A number of prioritization projects have identified key priorities for further research in Children's Palliative care (Quinn et al^{iv}) and care of children with severe neurological impairment (Dyskin et al 2020 personal correspondence)

Background LauraLynn Ireland's Children's Hospice

LauraLynn, Ireland's Children's Hospice, is the only children's hospice in the Republic of Ireland, providing palliative care to children with life-limiting conditions (aged 0-18 years) and their families from all across Ireland. Opened in 2011, in 2021 the service is marking 10 years of providing palliative care and support for children with life-limiting conditions and their families from all across Ireland. Since its opening LauraLynn has cared for 489 children and their families including parents, brothers, sisters, grandparents and wider family members.

The LauraLynn Hospice Model of Care aims to ensure that The Right Child, receives the Right Care, at the Right Time, in the Right Place, by the Right Team. The care provided is safe and effective, responsive to needs, and delivered in location of choice, by a caring and compassionate team. An interdisciplinary Hospice Care Team provides support to the child and the family to help meet their specific needs using our five pillars of children's hospice care:

- Direct Care
- Symptom Management
- Family Support
- End-of-Life Care
- Bereavement Support

LauraLynn's current strategic plan – Building a Community of Care (2019-2023) - sets out our roadmap for the development of the service and our ongoing commitment to providing high quality care to children with palliative care needs in Ireland. Building research capability through innovation and collaboration, both nationally and internationally is a key strategic driver of the plan.

The introduction of The McKenna Scholarship – in honour of Jane and Brendan McKenna, founders of LauraLynn following the tragic loss of their two daughters Laura and Lynn – aims support the expansion

of the knowledgebase of Children's Palliative Care and is a major new initiative as part of LauraLynn's research ambition.

1 - OVERVIEW OF THE SCHOLARSHIP

- 1.1. The McKenna Scholarship "The Scholarship" is a one-off scholarship in recognition of the 10-year anniversary of the opening of LauraLynn Children's Hospice (LauraLynn).
- 1.2. The aim of the McKenna Scholarship is to support a suitably qualified MD or PhD candidate ("The Scholar") to pursue full-time research in the area of Children's Palliative Care (CPC).

2 - GENERAL CONDITIONS OF THE SCHOLARSHIP

- 2.1. The research project must commence by 1 October 2021 and be completed within 2 years for a MD or 3 years for a PhD. The project duration may only be deferred for reasons of an eligible career break, including but not limited to maternity leave, paternity leave, adoptive leave, sick or carers leave.
- 2.2. The Scholarship will be subject to these Terms and Conditions and any supplementary conditions set out in the award offer. If any of these Terms and Conditions are breached, LauraLynn reserves the right to suspend or terminate the award and may require reimbursement of payments already made.
- 2.3. The Scholarship will be awarded to an individual Scholar who must be formally affiliated with a Higher Education Institution (HEI) in the Republic of Ireland.
- 2.4. The HEI will be responsible for ensuring that The Scholar has access to effective procedures for resolving problems arising from the administration or supervision of The Scholarship. Serious problems with supervision from the Academic Supervisor should be addressed using the relevant HEI grievance process.
- 2.5. If The Scholar is unable to pursue their project in accordance with these Terms and Conditions, the Scholar and their supervisor must inform LauraLynn and their HEI.

3 - LOCATION OF THE SCHOLARSHIP

- 3.1. The Scholar will not be an employee of LauraLynn Children's Hospice.
- 3.2. The Scholar must be affiliated with an Irish Higher Education Institution in the Republic of Ireland
- 3.3. An academic supervisor at an Irish HEI/RPO must be identified to supervise The Scholar before applying for The Scholarship.
- 3.4. The HEI is responsible for the provision of professional guidance, support and mentoring to the Scholar.
- 3.5. The HEI associated with the research project cannot be changed without discussion with and the agreement of LauraLynn.
- 3.6. LauraLynn will not be liable for any expenses related to the research project in excess of the agreed funding within the Scholarship proposal.

4 - RESPONSIBILITIES OF THE ACADEMIC SUPERVISOR

- 4.1. The McKenna Scholarship requires that The Scholar be supervised by an academic supervisor based at the same HEI as The Scholar.
- 4.2. LauraLynn requires The Scholar to submit a progress report every 6 months to the LauraLynn Research Committee.
- 4.3. It is the responsibility of the Scholar's primary academic supervisor to ensure that if the Scholar leaves their HEI or is not dedicating sufficient time or effort to the award, LauraLynn is informed immediately.

5 - RESPONSIBILITIES OF THE HIGHER EDUCATION INSTITUTE

- 5.1. In the case of the scholarship, it is a requirement of these Terms and Conditions that the HEI holds a contract with the Scholar to cover the funding term.
- 5.2. The HEI must accept full accountability for managing, monitoring and controlling all research work funded under The Scholarship and financial management of the Scholarship fund.
- 5.3. The HEI must ensure that an academic supervisor is appointed with responsibility for supporting and guiding the Scholar. This academic supervisor would normally be a principal investigator.
- 5.4. The HEI is responsible for providing the facilities and access to the equipment needed for the Scholar to carry out the research, ensuring that all items of equipment and materials provided for the award are adequately maintained and are accessible.

6 - FINANCIAL ADMINISTRATION AND AUDIT

- 6.1. While the Scholarship will be awarded to an individual Scholar, the scholarship fund will be administered through the appropriate office within their HEI.
- 6.2. Subject to compliance with these Terms and Conditions and to receipt of satisfactory progress reports, the award fund will be paid to the Scholar's HEI, quarterly in advance, with the first instalment to be made as soon as the award commences. It is the HEI's responsibility to coordinate payment of the award fund to the Scholar in a timely manner.
- 6.3. The HEI is responsible and accountable for the proper use of the award fund. No funds may be used by the HEI to cover overhead or administrative costs. The HEI must ensure proper financial management of the award and accountability for the use of public funds.
- 6.4. No additional funds will be made available to The Scholar other than outlined in the original Scholarship Offer.
- 6.5. Funds allocated to fees may not be reallocated to other financial costs.
- 6.6. Scholarships are classified as "scholarships" under Irish Tax Law and as such Tax or Social Insurance charges do not apply. All award holders must comply with the Irish laws and regulation on taxation. Compliance with Irish laws and regulations on taxation will be a matter for the Scholar, the HEI and the Office of the Revenue Commissioners.
- 6.7. Funding will only be provided for the research project as presented in the application. The written consent of LauraLynn must be sought in advance of any significant changes to the

research project during the funding term. Such requests will be reviewed by the Research Committee and the Research Committee's decision about whether to approve the proposed change(s) will be final.

- 6.8. Funds may only be carried forward from the previous year of the award under the eligible direct research expenses heading. It will not be possible to carry forward funds awarded for the salary/stipend, or unused fee contribution.

7 - REVIEW OF PROGRESS

- 7.1. The Scholar will be required to submit a comprehensive progress report to the LauraLynn Research Committee every 6 months.
- 7.2. It will be the responsibility of the Scholar to make sure that all progress reports are submitted on time, failure to do so may result in suspension or cessation of scholarship funding.
- 7.3. The format for these reports should include;
- research progress and outputs
 - outreach activities
 - research dissemination
 - any adverse events related to the research project
- 7.4. LauraLynn reserves the right to suspend or terminate the award if the Scholar fails to provide biannual progress reports, if there is evidence that the Scholar is not dedicating adequate time or effort on the research project or if LauraLynn has reasonable concern that continued funding of the project may be associated with adverse impact on children or services users or on the reputation of LauraLynn Children's Hospice.
- 7.5. It will be the responsibility of the Scholar's academic mentor/supervisor to ensure that if the Scholar leaves their host institution or is not dedicating sufficient time or effort to the research Project that LauraLynn is informed immediately.

8 - ADDITIONAL DUTIES OUTSIDE THE REMIT OF THE AWARD

- 8.1. The Scholar's first duty is to the successful completion of the research project for which they have been awarded the McKenna Scholarship.
- 8.2. The Scholar should be engaged in **full-time research during the funding term.**
- 8.3. LauraLynn acknowledges that teaching experience can be of benefit to the academic development of a student and may support the acquisition of skills essential for knowledge transfer. Thus teaching duties may be considered as a valuable addition to the Scholars career and may be allowable during the duration of the scholarship provided the work does not negatively impact on the Scholar's ability to complete the research project.
- 8.4. Where Award holders undertake teaching duties, they should be appropriately remunerated by their Irish HEI. Any such payments will not affect the Scholar's total amount of award. Compliance with Irish laws and regulations on taxation will be a matter for the Scholar, the Irish HEI and the Office of the Revenue Commissioners.

- 8.5. Occasionally the Scholar may be required to attend events or meetings arranged by LauraLynn and may be asked to present their research at educational events organised by LauraLynn (if it is deemed appropriate to the stage of their research project).
- 8.6. LauraLynn must be referenced as the funder of the research project during all events of information dissemination, including presenting at conferences, lectures, and publications.

9 - SUSPENSION OF THE AWARD

- 9.1. It is expected that The Scholar will complete their research project in the agreed timeframe however it is recognised that there may be reasonable grounds for a break in the project. These reasons may include maternity, paternity or adoption leave, sick or carers leave. Where prolonged leave is taken, it should not exceed 1 year. No scholarship funding would be available during the leave period.
- 9.2. Additional registration or academic fees incurred by the Scholar as a result of suspending their award are a matter for agreement between the Scholar and their HEI. LauraLynn will not be liable for any such additional fees.

10 - TERMINATION OF THE AWARD

- 10.1. LauraLynn recognises that, for personal or professional reasons, an award holder may wish to terminate their award prematurely. In this event all funding will be discontinued and LauraLynn may pursue the Scholar for the Scholarship funds paid up to the date of discontinuing the project.

11 - COMPLETION OF THE McKENNA SCHOLARSHIP

- 11.1. Scholarship funding will cease at the agreed end date of the Scholarship or on the date of submission of the final thesis, whichever comes first.
- 11.2. The Scholar is required to inform LauraLynn of the successful completion of their project in writing. LauraLynn is also entitled to obtain this information directly from the Scholar's HEI.

12 - ETHICS AND QUALITY ASSURANCE

- 12.1. Research activity funded under the McKenna Scholarship must be contributing to the evidence and knowledge base of Children's Palliative Care and in accordance with the LauraLynn Strategy 2019—2023.
- 12.2. The HEI is responsible for ensuring that ethical issues relating to the Scholar's research are identified and brought to the attention of the relevant approval or regulatory body.
- 12.3. Research Ethic Committee Approval at the HEI and other relevant institutions must be obtained before any research requiring approval begins.
- 12.4. All research must be undertaken with due regard to the Health Research Regulations 2019, Data protection and GDPR legislation.

- 12.5. Where necessary, the Scholar will be required to confirm that they have obtained the appropriate ethical approval to carry out their research project from the relevant approval or regulatory body at their HEI.
- 12.6. The HEI is responsible for ensuring that the Scholar's research complies with all national and international regulation requirements governing the use of sensitive materials or processes.
- 12.7. The Scholar and their HEI must follow good practice on data protection, management and security. LauraLynn cannot be held legally liable for any regulatory breaches.

13 - ACKNOWLEDGEMENT OF FUNDING

- 13.1. LauraLynn does not make any claim to intellectual property arising from the award.
- 13.2. All publicity and knowledge transfer, including interviews, lectures, presentations, publications, online materials, press releases, etc. associated with or arising from the research undertaken by the Scholar must contain acknowledgement of funding received from LauraLynn. Where appropriate, LauraLynn's logo should be included.
- 13.3. LauraLynn may choose to actively promote the McKenna Scholarship and the Scholar via the LauraLynn Social Media channels.

14 - SCHOLARSHIP AWARD FUNDS

- 14.1. An annual tax-free stipend of €18,500 euro per year. This award is in-line with stipends paid by the Irish Research Council following a recent increase on the direction of the Minister for Higher Education.
- 14.2. A contribution to fees paid to the HEI up to a maximum of €6,000 per annum. Any differential must be paid by the scholar and/or HEI.
- 14.3. Eligible direct research expenses of **€2,000 per annum** to enable the scholar to carry out the research project.
- 14.4. Only vouched expenses incurred in carrying out the research project during the agreed funding term are permissible.
- 14.5. Eligible direct research costs may include but are not limited to:
 - materials and consumables
 - equipment costs
 - software and hardware critical for the proposed research
 - A maximum limit of €1000 for computers or laptops applies and this must be purchased within the first year of the award
 - reasonable travel, subsistence, and conference costs
 - skills training directly related to the research project
 - publishing and write-up costs
- 14.6. Living costs (e.g. rent) are not permissible
- 14.7. The HEI must ensure proper financial management of the award and accountability for the use of public funds. It should also ensure that all unspent funds are returned to LauraLynn at the end of the funding term.

15 - DURATION OF THE POSTGRADUATE AWARD

- 15.1. The award will support suitably qualified research MD or PhD candidates pursuing, or intending to pursue, **full-time** research in a subject related directly to Children's Palliative Care in line with the LauraLynn Strategy 2019-2023.
- 15.2. An award holder who is a new entrant to the postgraduate degree for which they are seeking funding is entitled to apply for funding for the full duration of the degree up to 3 years.
- 15.3. For award holders who have already completed part of the doctoral degree for which they are seeking funding, the duration of funding to be awarded will commence from the date of award of the Scholarship and last for up to 3 years or until completion of the project whichever is shortest.

ⁱ Goldman A et al Palliative Care for Children Second Edition. Chapter 39 Page 441. 2012.

ⁱⁱ Downing J et al Priorities for global research into children's palliative care: results of an International Delphi Study. BMC Palliative Care 2015

ⁱⁱⁱ Quinn C et al Prioritisation of future research topics in paediatric palliative care in Ireland: a Delphi Study. International Journal of Palliative Nursing. 2017.

^{iv} Quinn C et al Prioritisation of future research topics in paediatric palliative care in Ireland: a Delphi Study. International Journal of Palliative Nursing. 2017.

^v Diskin et al 2020 . Research Priorities for children with neurological impairment and medical complexity. Submitted for publication. Personal correspondence