



**Parkinson's**  
Association of Ireland

**By-Laws for the National Research and Advocacy Sub-Committee of the  
Parkinson's Association of Ireland**

**Company Registration Number: 123532**

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The following document pertains to information regarding the by-laws for the national research and advocacy sub-committee for the Parkinson's Association of Ireland.

A. Terms of Reference

The research and advocacy sub-committee are responsible for:

- Advocating for the Parkinson's Association of Ireland and general membership in a formal manner.
- Engaging with relevant parties (e.g. Health Service Executive) to advocate for services for people with Parkinson's
- Collaborating with external parties to conduct meaningful research projects on behalf of the Parkinson's Association of Ireland.
- Identifying meaningful research questions within the association to identify gaps in services.
- Identifying and applying for research grants and funding to conduct research pertaining to the Parkinson's.

B. The research and advocacy sub-committee for the Parkinson's Association of Ireland shall consist of 8-10 members, and shall include:

- Four (4) current PAI members
- One (1) Medical Professional
- One (1) Registered Dietician
- One (1) Speech and Language Therapist
- One (1) Occupational Therapist
- Two (2) prospective members with experience in grant and funding applications

Note: The two aforementioned members with experience in grant and funding applications can have dual roles within the sub-committee (e.g. current PAI member, medical professional, registered dietician, speech and language therapist, occupational therapist)

Note: Only two members of the Board of Directors can simultaneously serve on the sub-committee at any one time, and that is to act as (i) lead and (ii) a supportive observer of the sub-committee. The second Board Member should act as lead in the absence of the primary serving Board Member.

Note: There is no rule against current PAI members simultaneously serving on branch committees.

C. The structure of roles shall be as follows:

- One (1) Chair / Lead of the sub-committee (Board Member)
- One (1) Secretary of the sub-committee
- One (1) Treasurer of the sub-committee
- Four (4) Regional Liaisons within the Parkinson's Association of Ireland
- Four (4) Health Service Executive (HSE) Liaisons
- Two (2) Grant and Funding Co-ordinators

Note: Dual roles are permitted within the sub-committee. At any one point, a sub-committee member can hold a maximum of two roles. The following combination of roles are permitted within the sub-committee:

- Chair / Lead + any other role (bar Secretary & Treasurer)
- Secretary + any other role (bar Chair / Lead & Treasurer)
- Treasurer + any other role (bar Chair / Lead & Secretary)
- Regional liaison + grant co-ordinator
- HSE liaison + grant co-ordinator

The following combination of roles are not permitted within the sub-committee:

- Regional liaison + HSE liaison
- Chair / Lead + Secretary
- Chair / Lead + Treasurer
- Secretary + Treasurer

D. The primary duties and responsibilities for each individual role are as follows:

i. Chair / Lead

- There is to be one formal designated lead of the sub-committee. The duties and responsibilities of the lead include, but are not limited to:
  - o Coordinating meetings between the sub-committee.
  - o Providing regular updates of minutes, decisions and actions to both the Board of Directors and Chief Executive Officer of the association.
  - o Ensuring any study that requires ethical approval coincides with current General Data Protection Regulation (GDPR) guidelines.
  - o Protecting the anonymity of the Parkinson's Association of Ireland members should they choose to participate in the study.
  - o Acting in the best interest of the organisation in terms of research and advocacy. For example, the lead of the research sub-committee must not agree

to collaborative studies with external organisations that put any member of the Parkinson's Association of Ireland in danger.

ii. Secretary

- There is to be one designated member of the sub-committee to act as Secretary of the sub-committee. The duties and responsibilities of the lead include, but are not limited to:
  - Assisting the Chair / Lead in their duties.
  - Distributing the agenda before each sub-committee meeting.
  - Taking minutes during each sub-committee meeting.
  - Drafting the sub-committee report to be sent to the CEO and Board of Directors following each sub-committee meeting.
  - Ensuring the sub-committee report is sent by the Chair / Lead to the CEO and Board of Directors following each sub-committee meeting.

iii. Treasurer

- There is to be one designated member of the sub-committee to act as Treasurer of the sub-committee. The duties and responsibilities of the lead include, but are not limited to:
  - Maintain adequate books regarding expenditure for the sub-committee.
  - Submit account books as requested by the CEO or Board of Directors.
  - Provide correct invoices and receipts for expenditure.

iv. Regional Liaisons

- Four members of the Parkinson's Association of Ireland will act as regional liaisons. There will be one for Leinster, Munster, Connacht and Ulster (who may assist Connacht in their duties). The duties and responsibilities of regional liaisons include, but are not limited to:
  - Ensuring dissemination of information regarding research studies (recruitment, study design, objective, external collaborations) to branches in allocated respective regions.
  - To coordinate and act as regional lead for advocacy projects within their region on behalf on the Parkinson's Association of Ireland.
  - To work with regional coordinators to answer any and all queries regarding research and advocacy that arise from members or branches within their respective region.

v. Health Service Executive Liaisons

- Four members of the research and advocacy sub-committee will act as liaisons with the Health Service Executive (HSE). This will be the medical professional, registered dietician, speech and language therapist, and occupational therapist. Their duties and responsibilities include, but are not limited to:
  - Providing a voice for our members and organisation with the larger HSE.
  - To raise awareness regarding Parkinson's Disease within the HSE.
  - To raise awareness regarding available services for people with Parkinson's.
  - To advocate for improved services.
  - To advocate for formal funding from the HSE.
  - To advocate for collaborative service delivery between the HSE and PAI.

vi. Grant and Funding Coordinators

- Two members of the sub-committee will be responsible for coordinating grant and funding applications. Their duties and responsibilities include, but are not limited to:
  - Completing formal grant and funding applications on behalf on the organisation.
  - Ensuring the other sub-committee members are aware of available grant and funding opportunities so that this can be presented to the Board of Directors and Chief Executive Officer.
  - Keep record of what grants (with details of monetary value and donor/contributor) have been applied for and their respective outcome (successful / unsuccessful).

vii. All Sub-Committee Members

- It is the duty and responsibility of all sub-committee members to:
  - Act in the best interest of the Parkinson's Association of Ireland and general membership at all times.
  - To advocate for our members and association.
  - Advertise and/or recruit for available positions within the sub-committee.
  - To provide one formal annual update to the general membership of the association, in addition to the regular updates provided to the Board of Directors and Chief Executive Officer of the organisation.
  - Ensure the sub-committee member in question has signed a declaration (please see separate document) to indicate they understand the roles and responsibilities, and will act in the best interest of the membership and association at all times.

## E. Meetings

- It is expected that the sub-committee will meet 4 times during the calendar year to discuss research and advocacy projects.

Note: Meetings should be scheduled at least two weeks prior to an upcoming Board of Directors meeting to allow adequate time for the Board of Directors to review the sub-committee report before the next Board of Directors meeting.

- The following rules apply to sub-committee meetings:
  - o Dates of meetings must be agreed in advance, and a schedule sent to the Board of Directors and Chief Executive Officer.
  - o Meetings must aim to be conducted in a virtual format (e.g. Zoom) to facilitate attendance.
  - o Minutes must be kept of each meeting (attendees, topics discussed, actions, decisions).
  - o Minutes must be sent to the Board of Directors and Chief Executive Officer following each meeting.
  - o A formal update (via document or presentation) must be made to the general membership once a year with regards to ongoing research and advocacy projects. The presentation can be recorded and placed on the website.

Note: The Chief Executive Officer or any member of the Board of Directors can attend a scheduled meeting as an observer.

## F. Prospective Candidates for the Research and Advocacy Sub-Committee

- The sub-committee is responsible for the advertisement and/or recruitment of prospective members for available positions within the sub-committee.
- The advertisement process is as follows:
  - o Advertisement for regional liaisons must be communicated to the general membership (via email and/or post and/or newsletter and/or website).
  - o No formal advertisement is needed for position(s) of HSE liaison and often this will occur via informal manners through healthcare professionals that have previous correspondence or experience with the Parkinson's Association of Ireland.
  - o No formal advertisement is needed for that of grant and funding coordinator(s).

- No formal advertisement for lead position is necessary, as it is projected the lead will be a serving sub-committee member. The position of lead must be filled by one of the two serving board members.
- The recruitment process is as follows:
  - Any potential candidates for available positions must be formally discussed among serving sub-committee members at a scheduled sub-committee meeting, in terms of their credentials and suitability for the position.
  - Following discussion, a formal vote must be taken by sub-committee members.
  - Credentials and outcome of vote must be noted in the minutes.
  - A formal letter (with Parkinson's Association of Ireland letterhead) must be sent to successful prospective candidates to invite them to join the sub-committee. Documentation must be kept of this correspondence and acceptance / refusal of the offer.
  - All new (and existing members) must sign a declaration (see separate document) indicating they understand the roles and responsibilities, and will act in the best interest of the membership and association. Formal record must be kept of these documents.
  - The Chief Executive Officer and Board of Directors must be made aware of any new appointments.

Note: The aim of the sub-committee is to have a broad representation across the membership for the four (4) serving PAI member positions.

#### G. Resignation from the Sub-Committee

- Any member wishing to resign from the sub-committee must:
  - Make their desire to resign known at a scheduled sub-committee meeting. Documentation of their announcement, reasoning for resignation, and acceptance by the remaining members of the sub-committee must be noted in the minutes.
  - Allow for a period of two (2) months or sixty (60) days from date of announcement to date of formal resignation. This is to allow adequate opportunity to identify and invite a suitable replacement for the available position.

Note: The resignation of any member from the sub-committee must be made known to the Chief Executive Officer and Board of Directors in writing (email).

## H. Disputes within the Sub-Committee

- Any disputes within the sub-committee must be brought to the attention of the Board of Directors and Chief Executive Officer. If a sub-committee member is deemed to have acted against the best interests of the Parkinson's Association or Ireland or the general membership, their position on the sub-committee will be brought for review and vote by the Board of Directors. A vote in favour from the Board of Directors will lead to a request for the immediate resignation of the member from the research and advocacy sub-committee.

## I. Length of Service

- A member of the sub-committee can serve for a maximum of three years (before formal review). After this, should a member wish to stay on, a request must be made to the Board of Directors for an extension. If the request is approved, a member can serve on the sub-committee for another 3 years. A member is permitted to submit only one request for extension. Therefore, the maximum a member can serve on the sub-committee is 6 years in total (3 standard + 3 extension).

## J. Research Studies Involving the General Membership

- All research studies that involve the general membership of the Parkinson's of Ireland must ensure to meet the following requirements:
  - Must comply with GDPR regulations.
  - Must protect the anonymity of members.
  - Must not discriminate based on sex, creed, race, ethnicity, or locality.
  - Must be open for all members to participate (dependent on the premise of the study e.g. females / males, young onset Parkinson's, etc.)
  - Must include a declaration of participation to be signed by respective members.
  - Must ensure the personal and sensitive information of members is protected at all times.
  - Must ensure appropriate disposal of personal and sensitive information of members upon completion of the study.
- If any of the above requirements are breached, the position of responsible sub-committee members will be brought for formal review by the Board of Directors.



## K. Research Studies and Proposals

- All research studies and proposals must be:
  - Discussed at a scheduled sub-committee meeting
  - Proposals must be put to vote among the sub-committee. Proposals require a two-thirds majority vote to be accepted.
  - Furthermore, proposals must have the confidence of the Board of Directors. The lead (Board member) can provide approval on behalf of the Board of Directors. This approval can be immediate or deferred for further discussion at a Board of Directors meeting.
  
- Formal documentation must also be kept for each research study regarding:
  - Principal Investigator / lead of study
  - Study Aim / Objective
  - Study Methodology
  - Whether Ethics are required or not
  - Whether there is an external collaboration or not
  - Participants and what may be required of participants

Note: Formal documentation must be signed and submitted by the Principal Investigator for record within the sub-committee

## L. Expenses

- Expenses incurred for the calendar year for 2021 will be accepted on a rolling basis, per discussion with the Chief Executive Officer. Approval of expenses will follow similar financial policies and procedures that exist for branches. From 2022, expenditure for the sub-committee will be budgeted in the formal budget for the association.

## M. Changes to the By-Laws

- Changes to the by-laws can be:
  - Proposed by any member of the sub-committee
  - Proposed by any member of the Board of Directors
  
- Changes proposed by a member of the sub-committee must be discussed and voted on at a scheduled sub-committee meeting, with documentation of discussion and vote noted in the minutes. A vote in favour (two-thirds, or seven members of the sub-committee) of the proposal allows the proposition to be sent to the Board of Directors

for formal review and vote among the Board of Directors. Appropriate reasoning for approval or disapproval by the Board of Directors will be provided to the sub-committee.

- Changes proposed by a member of the Board of Directors must be done with full transparency and discussion with the research and advocacy sub-committee. A formal vote need not be held among the sub-committee if proposed by a member of the Board of Directors, with only a formal vote by the Board of Directors required. A vote in favour (two-thirds) from Directors is required for approval.

**NB: Please ensure all members of the sub-committee have signed a declaration (please see separate document), and that a record is kept of the declaration.**

**End of document.**

**(Updated June 2021)**