

CHILDHOOD ARTHRITIS & RHEUMATOLOGY RESEARCH ALLIANCE
(CARRA)

Operating Procedures

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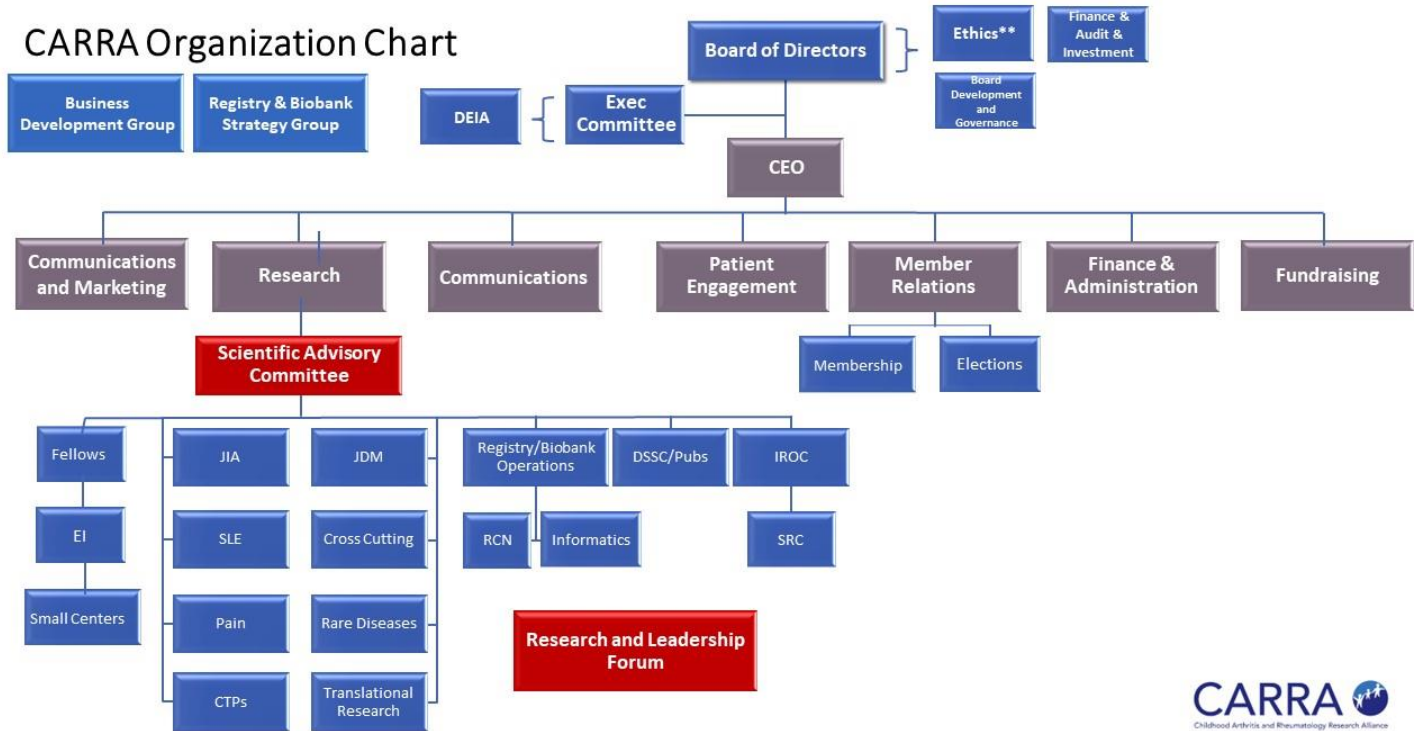
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COMMITTEES AND GROUPS

1. Board Committees and Board Advisory Committees

a. Executive Committee:

The Committee is chartered to exercise powers of the Board in the oversight of the management of business and affairs of CARRA, including financial matters so that the Board retains the ability to act through the Executive Committee (EC) between formal Board meetings if deemed necessary. The Committee provides reports and recommendations to the full Board for review and approval. (See appendix for full EC Charter)

Composition: The Executive Committee shall be composed of four (4) voting members and the CEO of CARRA (as non-voting). Terms of office shall be two (2) years. Executive Committee members are members of CARRA Board of Directors.

i. President

- The President is a voting member of the Executive and Scientific Advisory Committees
- The President automatically becomes Immediate Past President upon expiration of his/her term as President.
- The Vice President automatically becomes President upon expiration of the current President's term.

Responsibilities:

- Serve as Chair of the Executive Committee.
- Serve as *ex officio* member of the Finance Committee
- Partner and oversee the work of the Chief Executive Officer
- Co-Chair the Scientific Advisory Committee
- Serve as Executive Committee Liaison to 2-3 research committee chairs which rotate annually

ii. Vice President

- The Vice President is a voting member of the Executive and Scientific Advisory Committees
- Following one term as Vice President, this individual then serves one term as President, followed by one term as Immediate Past President

Responsibilities:

- Serve as a member of the Executive Committee.
- Co-chair the Scientific Advisory Committee
- Chair the Membership Committee
- Serve as Executive Committee Liaison to 2-3 research committee chairs which rotate annually

iii. Treasurer/Finance Chair

- The Treasurer/Finance Chair is a voting member of the Executive and Scientific Advisory Committees

Responsibilities:

- Serve as the Chair of the Finance Committee
- Serve as Chair of the Investment Committee
- Serve as Executive Committee Liaison to 2-3 research committee chairs which rotate annually

iv. Immediate Past President

- The immediate Past President is a member of the Executive and Scientific Advisory Committees.
- At the expiration of a term as Immediate Past President, he/she is ineligible to serve on the Executive Committee for two (2) years.

Responsibilities:

- Serve as Chair of the Elections Committee
- Serve as Chair of the IROC
- Serve as Executive Committee Liaison to 2-3 research committee chairs which rotate annually

b. Ethics Committee (Advisory Committee to the Board)

i. Composition

The Committee will consist of between five (5) to nine (9) voting members.

- All voting members must also be current CARRA members.
- The Committee will include at least one (1) individual who is not a member of CARRA, appointed by the CARRA Board of Directors, as a non-voting member.

- One (1) member of the Board will serve as a non-voting member and as the Board liaison.
- The Committee shall elect a Chair by majority vote to serve a three-year term. A Chair may serve up to two (2) consecutive terms.

ii. Responsibilities:

In addition to any other responsibilities which may be assigned from time to time by the Board, the Committee is responsible for:

- Ensuring conformance to CARRA policies and directives that relate to CARRA's ethical standards and management of conflict of interest.
- Review and make recommendations regarding the ethics and professionalism of the organization, its officers, directors, and members.
- Review and make recommendations regarding any conflicts reported during the annual Conflict of Interest/Conflict of Commitment (COI/COC) disclosure process and reports of conflicts submitted by all CARRA Leaders. CARRA Leaders are defined as members of committees that include elected and/or appointed positions, including but not limited to: CTP Advisory Committee, Data and Sample Share Committee, Diversity, Equity and Inclusion (DEI) Advisory Committee, Elections Committee, Ethics Committee, Finance Committee, Internally Funded Research Oversight Committee (IROC), Membership Committee, Registry Parent/Patient Advisory Committee (RPAC), Research and Biobank Operations Committee (RBOC), Scientific Advisory Committee, Scientific Review Committee (SRC), members of the Board of Directors, Business and Industry Associate Members, and Staff.
- Review and, from time to time, propose modifications to the CARRA Code of Ethics and the CARRA Conflict of Interest Guidelines and develop information to educate the membership concerning the Code of Ethics and conflict of interest issues.
- Review charges alleging professional misconduct by members.

c. Board Development and Governance Committee:

i. Composition

The Committee consists of between three (3) and five (5) individuals:

At least three members will be directors of the Board, nominated by self or by one or more directors. The CEO of CARRA serves as an *ex officio* (non-voting) member of the Committee.

- Voting committee members serve two-year terms, renewable once. Following two consecutive terms, a member is ineligible for one term before being eligible again.
- Members' terms should be staggered so that all members are not replaced at the same time.
- The Chair of the Committee shall be nominated by the committee members.
- The Chair is responsible for leading the Committee, including overseeing the agenda, presiding over meetings, and reporting to the Board.

ii. Responsibilities:

- Report quarterly to the Board concerning its activities; and advise the Board of any developments that should have Board consideration.
- Review compliance with CARRA’s bylaws with regard to the Board and all Board committees.
- Recommend priorities for the composition of the Board.
- Develop recommendations for nomination and election processes for new directors; interview and review the qualifications and interests of prospective directors.
- Organize and facilitate the onboarding of new directors and officers.
- Organize educational sessions for the full Board at least once every two years particularly regarding Board operations, expectations, fiduciary obligations, and best practices of nonprofit boards.
- Lead the Board’s self-evaluation process, at least once every two years and share results with the Board.
- Create and follow a schedule for periodic review of CARRA’s governing documents and as needed, recommending changes to the Board.
- In collaboration with the Ethics Committee, propose strategies to the Board for managing perceived and actual conflicts of interest, and conflicts of commitment of directors.
- Recruit, orient, and train new Committee members.
- Representing the best interests of CARRA at all times; maintaining confidentiality regarding the Committee’s work; and avoiding conflicts of interest.

d. Finance Committee

i. Composition

The Committee consists of no more than nine (9) individuals:

- Three voting members who are also voting members of CARRA. These members are nominated by self or by other CARRA voting members, determined to be eligible by the Elections Committee, and subsequently elected by CARRA Voting Members.
- The Treasurer of CARRA will serve as Chair and as a voting member of this committee.
- Three voting members are appointed by the Board. One has expertise in finance or related field (Banking, insurance, etc.), one has expertise in financial statement preparation/review, and one is a patient/parent representative. These individuals may or may not be members of CARRA. One individual may not serve dual roles (e.g., Finance expertise and patient/parent rep).
- The CEO of CARRA serves as an ex officio (non-voting) member of the Committee.
- The President of CARRA serves as an ex-officio (non-voting) member of the Committee.

- The Director of Finance and Administration of CARRA serves as ex-officio (non-voting) member of the Committee.
 - All voting members (elected and appointed) serve three-year terms, renewable once, with the exception of the Finance Committee Chair, who serves one two-year term. Following two consecutive terms, a member is ineligible for one year before being eligible again.
- ii. Responsibilities:
- Provide fiscal oversight, including review of financial policy and procedures, compliance with accounting guidance and compliance with tax regulations and rules.
 - Serve as the Audit Committee of the organization.
 - Selection and compensation of the auditors
 - Review audit reports.
 - Receives and considers actions to recommend to the full board because of recommendations from the auditors about actions the nonprofit should take to improve its financial reporting and management practices, as needed.
 - Receives reports directly from the auditors (not the CEO or CARRA Staff) in connection with the audit’s findings.
 - Review long-range financial plan.
 - Review and forward to the Board of Directors the annual fiscal budget.
 - Review Cash Flow and Cash Flow projections.
 - Oversee the Investment Committee.
 - Reviewing, prior to execution, any contracts referred to the Committee by the Board.

2. Scientific Advisory Committee

The Scientific Advisory Committee (SAC) is a standing committee, chaired/co-chaired by the CARRA President and Vice President, whose primary charge is to ensure that CARRA, through its committees and workgroups, is focusing efforts on research and programs that will advance the CARRA mission according to the strategic plan and research agenda.

- i. Composition
- The Chairs of the Research Committees are voting members of the Scientific Advisory Committee. These individuals are elected by the members of the respective Research Committees
 - The Vice chairs of the Research Committees are non-voting members of the Scientific Advisory Committee and may be asked to attend the SAC call if the research committee chair is unavailable and can vote in their absence. These individuals are elected by the members of the respective Committees.
- ii. Responsibilities:
- Reviews committee and workgroup plans and progress on an annual basis and evaluates new projects that will utilize resources during planning and/or implementation.
 - Provides strategic advice and recommendations to the CEO/Board regarding current and planned research efforts and project development.

- The Committee has the authority to steer efforts in new and important directions, and to recommend termination of projects that do not align with the strategic plan and/or research agenda.
 - The SAC may convene special task forces to focus on emerging research trends and/or concerns.
 - The SAC acts only in an advisory capacity.
3. Research and Research Related Committees: SOWs are in the appendix.
- Juvenile Idiopathic Arthritis (JIA)
 - Systemic Lupus Erythematosus (SLE)
 - Juvenile Dermatomyositis (JDM)
 - Scleroderma/Vasculitis/Rare Diseases (RD)
 - Pain
 - Translational Research Committee (TRC)
 - Cross Cutting Research Committee (CCRC)
 - Consensus Treatment Plans Committee (CTP)
 - Early Investigators (EI)
 - Small Centers
 - Fellows
 - Research Coordinator Network (RCN)
 - Diversity, Equity, and Inclusion Advisory Committee (DEI)
4. Stakeholder Committees and Groups: Charters are in the Appendix
- a. Registry and Biobank Operations Committee (RBOC)
The RBOC will be co-chaired by one CARRA Registry PI and one CARRA Biobank PI selected and appointed by the CEO and Board. The RBOC voting members will include all CARRA Registry PIs, Biobank PI(s), CARRA Registry Scientific Director, CARRA Registry Assistant Scientific Director(s). Non-voting members will include CARRA staff including the Associate Director of Research Operations and invited guests.
 - b. Data, Sample, and Publications Committee (DSPC)
The DSPC will have 6 standing members. Members will include the Assistant Scientific Director of the CARRA Registry, a Registry Associate, Senior Director of Research Operations, Associate Director of Research Operations, an Informatics Associate, and the PI of the CARRA Biobank. The DSPC will be led by the Senior Director of Research Operations. DSPC service terms will be for the length of the member's larger role within CARRA.
 - c. Research and Leadership Development Forum (RLDF)
This advisory group shall include at least five members. Members are selected and appointed by the CEO and Executive Committee of the Board.
 - d. Registry and Biobank Strategy Group (RBSG)
This advisory group shall include at least six members. Members are selected and appointed by the CEO and EC.
 - e. Internally Funded Research Oversight Committee (IROC)

The Committee consists of up to seven (7) individuals. Members are selected and appointed by the CEO and EC. The Grants Manager of CARRA serves as an ex-officio (non-voting) member of the Committee. The Immediate Past President shall serve as the Chair of the IROC

f. Business Development Group

This advisory group should include at least five members. Members will be selected and appointed by the CEO, Senior Director of Research Operations, and the EC. Senior Director of Research Operations, Director of Development, CEO, EC Delegate, one (1) current or former Registry PI, one or two (1-2) Board members, and one or two (1-2) external members as appropriate.

g. Elections Committee

The Elections Committee will consist of up to 5 voting members, including the Past Chair of the Executive Committee who will serve as Chair of this Committee. CARRA Staff assigned to support the Committee and ad hoc participants will not have voting rights.

h. Membership Committee

The Committee consists of between 7 and 10 individuals and will strive to include representatives from a variety of following stakeholder groups including: Fellows, Study Coordinators, Early Investigators, Small Centers, Large Centers, 1 patient or caregiver member, DEIA Committee Vice Chair. The Vice President shall serve as the Chair of the Membership Committee.

5. Process for New Committees

- Ad hoc committees may be formed by majority vote of the Scientific Advisory Committee, as circumstances require. The formation of new standing committees requires amendment to the Operating Procedures and as such must be approved as described in Section V.C. of this document. Charters and descriptions of these committees are in the Appendix Section of this document.

MEMBERSHIP

1. Individual Membership

CARRA provides a diverse range of memberships, each tailored to cater to professionals actively involved in pediatric rheumatology research and/or care within the network of CARRA sites, academic healthcare institutions, and medical care facilities. A CARRA site refers to a healthcare center with one or more existing CARRA members. Individual Membership offers access to grant writing assistance for early investigators, the opportunity to attend the CARRA Annual Scientific Meeting without a registration fee, and the ability to serve as a Principal Investigator (PI) for a CARRA study. Individual Members may also take a leadership role in CARRA workgroups, participate in committees, and apply for access to CARRA Registry data and biospecimens. Additionally, Individual Members have access to administrative support for distributing CARRA-related surveys to the membership and have access to the exclusive CARRA Members-Only Collaboration Site, fostering a collaborative environment for research and networking.

Membership Responsibilities: All CARRA members are expected to actively engage in one or more research committees, contribute to relevant surveys and participate in elections, and adhere

to the established CARRA policies.

a. Membership Types and Eligibility:

Physician and Pediatric Rheumatology Investigator Member (Annual Dues: \$150)

This membership category encompasses the following individuals from CARRA sites, other academic healthcare institutions, and medical care facilities:

- Pediatric rheumatologists and physicians from diverse specialties
- Research scientists or healthcare professionals with an advanced degree who have either served as the Principal Investigator of a CARRA study or committed a minimum of 50% of professional effort to a field relevant to pediatric rheumatology for over five (5) years, with a publication record of at least three peer-reviewed articles in pediatric rheumatology or a related field.
- Postdoctoral researchers
- Emeritus and retired physicians and pediatric rheumatologists (Membership fees will be exempted for those holding the Emeritus title.)

Research and Health Care Professional Member (Annual Dues: N/A)

This membership category is open to the following individuals at CARRA sites or other academic healthcare institutions:

- CARRA Registry Research coordinators and other pediatric rheumatology research coordinators working at CARRA sites.
- Health care professionals (nurses, physical therapists, occupational therapists, social workers, etc.) and other research professionals (such as site regulatory coordinators) working at CARRA sites or other medical care facilities who do not meet criteria for "Physician and Pediatric Rheumatology Investigator Members."

Trainee Member (Annual Dues: N/A)

This membership is inclusive of individuals at CARRA sites or other academic healthcare institutions:

- Fellows participating in approved Pediatric Rheumatology fellowship programs in the US or Canada
- International physicians engaged in training programs with the aim of becoming pediatric rheumatologists
- Pediatric Residents with an interest in pediatric rheumatology
- Medical Students interested in pediatric rheumatology
- Graduate Students with an interest in pediatric rheumatology

After successfully completing their Fellowship, Trainee members are required to update their profiles accordingly. Following this update, they will be eligible for consideration as Physician and Pediatric Rheumatology Investigator Members.

2. Associate Membership

CARRA offers Associate Memberships. Associate Members can attend the annual meeting and other CARRA events. Associate Members may actively participate in research and stakeholder committees and workgroups (by invitation only). Associate Members have restricted access to

the CARRA Members-Only Collaboration Site. While associate members cannot apply for grants, access registry data, or request registry data and biosamples, their engagement in collaborative initiatives and events enhances the CARRA community. Please find details on the available categories below.

a. Associate Membership Types and Eligibility:

Nonprofit/Government Associate Member (Annual Dues: \$100)

This category encompasses leaders and/or staff, including patients and caregivers, from nonprofit or government organizations actively involved in endeavors related to pediatric rheumatology or a closely associated field. Leaders may include both paid and volunteer leaders, such as members of an organization's Board of Directors or advisory boards.

Patient/Caregiver Associate Member (Annual Dues: N/A)

Designed for individuals aged 18 or older interested in becoming research partners with CARRA, this membership category is tailored for patient/caregivers who do not qualify under any other CARRA membership category. Patient/caregiver leaders from other nonprofit and advocacy organizations are directed to consider the "Nonprofit/Government Associate Member" category.

Business and Industry Associate Member (Annual Dues: \$300)

This category accommodates individuals from for-profit companies specializing in the sale of health-related products or services, including pharmaceutical, biotechnology, and medical device companies. Eligible individuals include employees leading or actively engaged in portfolios relevant to pediatric rheumatology or a closely related field. Relevant portfolios may span experimental medicine, digital health, diagnostics, and device and medical data mining applications.

To qualify, applicants must:

- Possess an MD, PhD, or equivalent degree(s), or demonstrate high-level relevant expertise or ability.
- Provide the name of a supporting CARRA member endorsing their application for associate membership.
- Disclose affiliation and any potential or real conflicts when participating in CARRA activities.
- Business and Industry Associate Members must submit a COI/COC Disclosure Form. The Membership Manager will send this form prior to approving the membership.

3. Membership Application Process

To become a CARRA member, prospective applicants are required to fill out the membership application. During this process, applicants will be prompted to complete a concise application form, providing fundamental contact and demographic information. Additionally, applicants will be asked to share details about their involvement in CARRA-related research.

As part of the online application, individuals will be requested to:

- Describe your role and experience in pediatric rheumatology research.
- Specify your role (if any) in providing care for children with pediatric rheumatic diseases.
- Articulate how you envision engaging with CARRA as a member.

- Attest to having reviewed, understood, and agreed to adhere to the CARRA Code of Ethics, CARRA Publication and Presentation Guidelines, CARRA Conflict of Interests and Conflict of Commitment guidelines, and CARRA Data and Sample Sharing Policy.

After submission of the online application, the Membership Manager will conduct a thorough review to determine membership eligibility. Upon approval, the member(s) will receive a link to settle any outstanding dues, if applicable. Once the payment is successfully processed, members will be granted access to their membership portal, where they can find exclusive access to all communications and the members-only website. Associate members will be granted restricted access in their membership portal to ensure appropriate privileges.

4. Membership Renewal

Annually, members must renew their memberships by revisiting and updating their membership profiles settling any applicable dues. This involves validating current address(es), professional and personal demographics.

ELECTIONS: NOMINATIONS AND APPOINTMENTS

1. Board of Directors

- See Section 7.4 of CARRA Bylaws

2. Board Committees Chairs & Vice Chairs

The Board Committees include Executive Committee, Finance Committee, Board Development and Governance Committee, and Ethics Committee

a. Executive Committee

- Every two years, a rotation of leadership roles shall take place within the Executive Committee as follows: The elected Finance Chair automatically assumes the position of Vice President. The Vice President automatically assumes the role of President. The President transitions to the position of Immediate Past President. The Immediate Past President, after serving their term, will cycle off the Executive Committee and is no longer a member of the committee.

b. Finance Committee

- Every two years, a slate of nominations for the new Finance Chair is presented to the Board of Directors for approval.
- After BOD approval of the nominees, an election is held of all by CARRA Physician and Pediatric Rheumatology Investigator Members for the position of Finance Chair. The newly elected Finance Chair will be a voting member of the Executive Committee and the Board of Directors.

c. Board Development and Governance Committee

- The Committee Elects the Chair of this committee by majority vote.

d. Ethics Committee

- The Committee shall elect a Chair by majority vote to serve a three-year term.

3. Research Committee Chairs and Vice Chairs

- a. Election Process:
The elections for open Chair and Vice Chair Positions within CARRA Research Committees (RC) – including JIA, JDM, SLE, CCRC, Pain, RD, CTP, TRTC, EI, RCN, Small Centers, DEI and Fellows Sub-Committee, – are conducted annually.
- b. Position Availability:
 - Not all positions are open simultaneously; specific Research Committees have staggered election cycles.
- c. Voter Eligibility:
 - Only Physician and Pediatric Rheumatology Investigator members are eligible to vote during these elections.
- d. Exceptions to Voter Eligibility:
 - Exception #1: During the RCN committee chair and vice chair election, research and healthcare professional members can also participate.
 - Exception #2: During the Fellow Co-Chairs election, all CARRA Fellow members can participate.
- e. Term Duration:
 - The Chair and Vice Chair of each RC serve a standard three-year term, with the option to run for a second term.
- f. Voting Mechanism:
 - The Chairs and Vice Chairs are elected by a majority vote of all Physician and Pediatric Rheumatology Investigator members.
- g. SAC Representation:
 - The Chairs of the RCs become voting members of the Scientific Advisory Council (SAC).
- h. Leadership Limitations:
 - The RC Chair can serve as Chair of only one RC at a time.
 - The RC Vice Chair can serve as Vice Chair of only one RC at a time.

This policy aims to ensure a fair and representative election process for Chairs and Vice Chairs of CARRA Research Committees while accommodating exceptions for specific committees and promoting effective leadership within the organization.

4. Composition of Stakeholder Committees and Groups (Registry and Biobank Operations Committee, Data Sample and Publications Committee, Research and Leadership Development Forum, Registry and Biobank Strategy Group, Internally Funded Research Oversight Committee, Business Development Group, Elections Committee, & Membership Committee)

- a. Registry and Biobank Operations Committee (RBOC)
 - The RBOC will be co-chaired by one CARRA Registry PI and one CARRA Biobank PI selected and appointed by the CEO and Board. The RBOC voting members will include all CARRA Registry PIs, Biobank PI(s), CARRA Registry Scientific Director, CARRA Registry Assistant Scientific Director(s). Non-voting members

- will include CARRA staff including the Associate Director of Research Operations, and invited guests.
- b. Data, Sample, and Publications Committee (DSPC)
 - The DSPC will have 6 standing members. Members will include the Assistant Scientific Director of the CARRA Registry, a Registry Associate, Senior Director of Research Operations, Associate Director of Research Operations, an Informatics Associate, and the PI of the CARRA Biobank. The DSPC will be led by the Senior Director of Research Operations. DSPC service terms will be for the length of the member's larger role within CARRA.
 - c. Research and Leadership Development Forum (RLDF)
 - This advisory group shall include at least five members. Members are selected and appointed by the CEO and Executive Committee of the Board.
 - d. Registry and Biobank Strategy Group (RBSG)
 - This advisory group shall include at least six members. Members are selected and appointed by the CEO and EC.
 - e. Internally Funded Research Oversight Committee
 - The Committee consists of up to seven (7) individuals. Members are selected and appointed by the CEO and EC.
 - f. Business Development Group
 - This advisory group should include at least five members. Members will be selected and appointed by the CEO, Senior Director of Research Operations, and the EC. Senior Director of Research Operations, Director of Development, CEO, EC Delegate, one (1) current or former Registry PI, one or two (1-2) Board members, and one or two (1-2) external members as appropriate.
 - g. Elections Committee
 - The Elections Committee will consist of up to 5 voting members, including the Past Chair of the Executive Committee who will serve as Chair of this Committee. CARRA Staff assigned to support the Committee and ad hoc participants will not have voting rights.
 - h. Membership Committee
 - The Committee consists of between 7 and 10 individuals and will strive to include representatives from a variety of following stakeholder groups including: Fellows, Study Coordinators, Early Investigators, Small Centers, Large Centers, 1 Patient or Caregiver Member, and the Vice Chair of the DEIA Committee.

5. Committee Members Elections (Elections, Ethics, Finance, and Membership)

The elections for these positions are exclusive to Physician and Pediatric Rheumatology Investigator Members and follows the process described below:

- a. Membership Database Review:
 - Annually, the Membership Coordinator reviews expiring terms in CARRA's CRM database.
- b. Announce to Membership:
 - Notify members of open positions and call for nominations.
- c. Identification of Open Positions:

- Determine open committee positions based on Charter guidelines
- d. Nomination Period:
 - Allow members to self-nominate or be nominated by peers.
- e. Verification of Eligibility:
 - Nomination information is sent to the Election and Ethics Committee for review of eligibility.
- f. Candidate Applications:
 - Applicants are required to submit their application, which should include a NIH Formatted Biosketch, a photo, and a personal statement outlining their qualifications and goals relevant to the position for which they are seeking election. This information will be assessed by participants during the voting process.
- g. Voting Period:
 - Conduct electronic voting in spring.
- h. Tabulation of Votes:
 - Membership Coordinator tabulates and verifies results and reports results to the Elections Committee.
- i. Announcement of Results:
 - Communicate results to membership and express gratitude to participants.

CORPORATE PROVISIONS

1. Amendments

- Proposed amendments to CARRA Operating Procedures must be submitted to the Executive Committee for approval by majority vote. Proposed amendments so approved must then be presented to the Voting Membership for adoption by majority vote at the next regular meeting or by email.

[Research Committee Chair SOW](#)

[Research Committee Vice Chair SOW](#)