



## **CODE OF ETHICS OF THE CHILDHOOD ARTHRITIS AND RHEUMATOLOGY RESEARCH ALLIANCE**

### **Preamble**

The Code of Ethics for the Childhood Arthritis and Rheumatology Alliance (CARRA) is meant to apply to the entire CARRA organization including its leaders, members, staff, and volunteers. This Ethics Code is to be enforceable within the CARRA organization itself.

This Code shall provide guidelines which are to ensure that the reputation of the research organization CARRA and its leaders, members, and staff are maintained. A primary goal of this Code is to focus on the ethical issues that are pertinent to the scientific and educational missions of CARRA.

### **I. Organizational Ethics**

Pediatric rheumatology research is a moral practice and enterprise. Our work is built upon ethically sound foundations and must promote the well-being of children, adolescents, and families who participate in this research.

1. CARRA's mission is to improve the health, well-being and outcomes of children and adolescents with rheumatic disease through fostering and facilitating collaborative research in prevention, treatment and cure.
2. CARRA will hold scientific meetings that are of the highest scientific caliber and are devoid of undue external influence
3. CARRA's publications will reflect editorial independence and integrity as well as scientific rigor.
4. CARRA's leadership will be accountable to its members, patients, and families and all of its policies will be publicly disclosed.

### **II. General Principles of Medical Ethics**

These general ethical principles are accepted standards of professional conduct which CARRA members should follow in their relationships with colleagues, patients, families and the general public.

1. In the research endeavors of CARRA at individual institutions, CARRA members will provide competent medical care with compassion and respect for human dignity as well as patient and family rights. The best interest in the child participating in CARRA research is paramount.
2. Member's judgment in CARRA's research activities at CARRA meetings and at the individual institutions must not be influenced by economic interest.



3. CARRA members must uphold the highest standards of professionalism and honesty in all professional interactions and behaviors.
4. Members should maintain the highest standards of research integrity and respect the rights of children and adolescents as research subjects.
5. Members should safeguard the confidentiality of the professional/child and family relationship.

### III. Specific Principles

The rules and policies of ethics listed below are mandatory as standards of conduct for all CARRA members:

#### A. Rules and Policies for the Individual Member of CARRA

1. Members will comply with all the CARRA policies including but not limited to CARRA bylaws and Code of Ethics as well as all laws, government regulations and requirements of other organizations/bodies that govern the conduct of CARRA-related activities.
2. Members will ensure that all communications and statements to the media, other organizations, and other individuals preserve patient confidentiality and are accurate and not deceptive or misleading.
3. Members will not use the imprimatur of CARRA, its name or logo in a way that suggests that the member is speaking or communicating for the CARRA organization or that CARRA has endorsed any service, treatment, product, person, or idea without the consent of the CARRA leadership.
4. Conflicts of interest must be disclosed and appropriately managed-see CARRA Conflict of Interest (COI) Statement.
5. Members should act in the best interest of CARRA and perform their responsibilities with all reasonable care, due diligence, and honesty.
6. Members, staff, and volunteers are expected to communicate with appropriate manners and etiquette verbally and electronically in all CARRA activities and maintain the highest professional standards of behavior in interactions with research subjects, CARRA peers and colleagues, and CARRA staff.
7. CARRA members, staff, and volunteers should not engage in unethical or unauthorized activities. These activities include ones that are not appropriate and not in accordance with CARRA bellows, COI and COC statements, and other documents addressing the responsibilities of CARRA members, staff, and volunteers.
8. All CARRA staff and volunteers will abide by the same ethical, COI, and COC guidelines as the CARRA members.

### IV. Administrative Procedures

This part of the Code of Ethics delineates the structure and operation of the CARRA Committee on COI and Ethics. This part also discusses procedures of this committee and its related committees.



#### **A. The Committee on Ethics**

The Committee on Ethics is a subcommittee of the CARRA Steering Committee and consists of three members of the Steering Committee appointed by the CARRA Executive Committee. These members will be responsible for reviewing and recommending ethical and COI issues and actions for CARRA and educating the membership regarding the Code of ethics and COI. The members will respond to questions and inquires, and investigate issues and concerns as they arise, and make recommendations for action.

#### **B. Member Misconduct**

A CARRA member may be disciplined for professional misconduct such as a violation of the CARRA Code of Ethics and COI, by-laws, or policies, unauthorized use of CARRA's name, and/or in addition to any adverse action taken against a CARRA member by another entity due to a CARRA member's professional or personal activities, e.g., with respect to his or her license to practice medicine or censure due to fraud. Any charges must be in writing and directed to the Committee on Ethics and Conflict of Interest for a preliminary review. After this review, the committee will report its findings to the Steering Committee and ultimately the Board of Directors.

The Steering Committee will investigate the charges, and make recommendations to the Board of Directors regarding disciplinary action if warranted. If so, a special meeting will be convened. The member will be notified of this meeting at least 30 days before the meeting and given the opportunity to appear with or without counsel and present appropriate evidence at the meeting. After the meeting is held, the Steering Committee's appointed representative will develop a written report on the matter and any disciplinary action recommended that may include censure, probation, suspension, or expulsion. The Steering Committee must vote on these actions and an action must be contemplated only if an affirmative majority votes for the action. If the Steering Committee decides no action is required, the matter is closed.

If the vote is for a disciplinary action, the Steering Committee will communicate the action to the member and make recommendations regarding disciplinary actions to the Board of Directors. The member will be given a copy of the Steering Committee report. The member may appeal the decision to the Board of Directors who will reconsider the member's charge and the Steering Committee's decision and make a final decision on the appeal. As appropriate, the disciplinary action may be reported to various institutions relevant to governance and oversight of scientific misconduct.