Revised Resolution No. 17

COMMITTEE ASSIGNMENT: Health & Safety Re: Bill of Rights for Firefighters Participating in Research as Human Subjects

1	WHEREAS, the U.S. Department of Health and
2	Human Services codified regulations to protect
3	human research subjects in the Code of Federal
4	Regulations, 45 CFR 46; and
5	WHEREAS, the Belmont Report, produced by
6	The National Commission for the Protection of
7	Human Subjects of Biomedical and Behavioral
8	Research in 1979, established the basic ethical
9	principles and guidelines for the protection of human
10	subjects of research; and
11	WHEREAS, these principles are founded on
12	respect for persons, beneficence, and justice; and
13	WHEREAS, "respect for persons demands that
14	subjects enter into the research voluntarily and with
15	adequate information"; and
16	WHEREAS, showing lack of respect for persons
17	includes "withholding information necessary to make
18	a considered judgement, when there are no
19	compelling reasons to do so"; and
20	WHEREAS, respect for persons is clearly
21	communicated by regularly scheduled updates on
22	research progress and through timely delivery of
23	research results and which is certainly accomplished
24	when "there is an adequate plan for debriefing
25	subjects, when appropriate, and for dissemination of

26	research results to them,"; and
27	WHEREAS, beneficence is an obligation for
28	scientists to make efforts to secure the well being of
29	research subjects by maximizing possible benefits;
30	and
31	WHEREAS, "research also makes it possible to
32	avoid the harm that may result from the application
33	of previously accepted routine practices that on
34	closer investigation turn out to be dangerous"; and
35	WHEREAS, in research, justice is considered in
36	the sense of "fairness in distribution" or "what is
37	deserved"; and
38	WHEREAS, "an injustice occurs when some
39	benefit to which a person is entitled is denied without
40	good reason or when some burden is imposed
41	unduly"; and
42	WHEREAS, the National Academies of Sciences,
43	Engineering, and Medicine developed a report on
44	Returning Individual Research Results to
45	Participants: Guidance for a New Research
46	Paradigm; and
47	WHEREAS, this report describes the concept of
48	"helicopter research", where scientists "drop into
49	communities or people's lives, engage with them in
50	often very personal ways, and then take off, never to
51	be heard from again"; and
52	WHEREAS, scientists engaging in "helicopter
53	research" publish research papers and present at
54	conferences for their own professional benefit, while
55	"leaving a sense of frustration and loss" in these
56	communities when they "take but do not share"; and

57 WHEREAS, scientists have often engaged in 58 "helicopter research" with firefighters who are 59 unaware of the fundamental principles described 60 above; and 61 WHEREAS, the National Institutes of Health has 62 emphasized the importance of Community Based 63 Participatory Research (CBPR) in human subjects 64 research to prevent disrespect for persons, lack of 65 beneficence, and injustices; and 66 WHEREAS, CBPR is a collaborative approach to 67 research where scientists and firefighters collaborate 68 as equal partners on all aspects of a research project 69 including but not limited to: developing research 70 aims, study design/execution, design of preventative 71 interventions, and dissemination of research findings 72 in a comprehensive format within an agreed upon 73 timeframe; therefore be it 74 RESOLVED, That in order to protect their members participating in human subjects research, an 75 76 IAFF Local shall not endorse participation by their members in a human subjects research study unless 77 78 the research is conducted utilizing a CBPR approach; 79 and be it further 80 RESOLVED, That the CBPR approach shall include at least one member of the IAFF Local(s) 81 82 whose members are participants in an oversight 83 position with sufficient access and authority to 84 ensure protection of firefighter research subjects, and 85 if no member(s) of the participating IAFF local(s) are 86 available or willing to fill this position, a president of 87 a participating IAFF local may request that a District

88	Vice President appoint a District Representative to
89	fulfill the role; and be it further
90	RESOLVED , That the IAFF endorses the creation
91	and distribution of a "Bill of Rights for IAFF
92	Members Participating in Research as Human
93	Subjects" as stated below in order to protect
94	firefighters participating in human subjects research;
95	and be it further
96	RESOLVED, That this Bill of Rights can be
97	amended or expanded to increase protections for
98	firefighters participating in human subjects research;
99	and be it further
100	RESOLVED, That scientists must agree in
101	writing to abide by this Bill of Rights before an IAFF
102	Local endorses the participation of its members in
103	any research study; and be it further
104	RESOLVED , That IAFF Locals shall refuse to
105	participate in or endorse research conducted by
106	scientists who do not abide by this Bill of Rights; and
107	be it further
108	RESOLVED , That IAFF Locals shall report in
109	writing to the General President and/or his
110	designee(s), any scientist who fails to adhere to the
111	principles of this Bill of Rights; and be it further
112	RESOLVED , That the fundamental principles of
113	ethical human subjects research described above are
114	long established, and hence IAFF members can
115	report scientists retrospectively, for incidents that
116	occurred before the adoption of this resolution; and
117	be it further
118	RESOLVED, That such scientists, at a minimum,

$ \begin{array}{r} 119\\ 120\\ 121\\ 122\\ 123\\ 124\\ 125\\ 126\\ 127\\ 128\\ 129\\ 130\\ 131\\ 132\\ 133\\ 134\\ 135\\ 136\\ 137\\ \end{array} $	 will be sent Letters of Concern by the IAFF, specifically identifying past departures from these well-established scientific practices, along with a copy of this Resolution demanding compliance with its terms in the future, to protect IAFF members; and be it further RESOLVED, That the "Bill of Rights for IAFF Members Participating in Research as Human Subjects" is as follows: (a) This Bill of Rights was created in order to protect IAFF members who choose to participate in human subjects research by making them aware of fundamental principles that must be followed in research as outlined in the code of Federal Regulations 45 CFR 46, the Belmont Report, the National Academies of Sciences, Engineering, and Medicine report on Returning Individual Research Results to Participants: Guidance for a New Research Paradigm, and the principles of
138	Community Based Participatory Research
139	(CBPR).
140	(b) These fundamental principles are as follows:
141	(c) Respect for Persons – Respect for persons
142	demands that firefighters enter into research
143	voluntarily and with adequate information about
144	who is conducting the research, where the
145	research is being conducted, and the research
146	aims
147	(d) Where scientists are aware that firefighters
148	have not been provided with adequate information
149	or have been misled, respect for persons demands

150	that scientists take action to adequately inform
151	firefighters.
152	(e) Beneficence – Scientists are obligated to make
153	efforts to secure and advance the well being of
154	firefighters at large by maximizing the possible
155	benefits of research.
156	(f) Maximizing the possible benefits of research
157	includes reporting back research findings to
158	firefighters in a comprehensible format within a
159	timeframe agreed upon by both firefighters and
160	scientists before collection of biological or
161	environmental samples.
162	(g) At the time of study enrollment, scientists
163	shall provide firefighters with a written and verbal
164	statement that includes:
165	i. Whether or not they currently have funds to
166	analyze the biological or environmental samples
167	they intend to collect.
168	ii. A plan with a timeline to report back
169	aggregate and individual (where possible)
170	research results to firefighters.
171	iii. A plan to develop preventative interventions
172	based on research results to better firefighter
173	health and safety.
174	iv. How to file a complaint with the Institutional
175	Review Board (IRB) governing the study, and
176	how to file a complaint with the agency funding
177	the study (e.g. NIEHS, NCI, FEMA, NSF, etc.).
178	(h) Justice – In research, justice is considered in
179	the sense of "fairness in distribution" or "what is
180	deserved" and an injustice occurs when some

181	hanafit to which a narron is antitled is denied
	benefit to which a person is entitled is denied
182	without good reason or when some burden is
183	imposed unduly.
184	(i) Scientists shall not publicize or publicly
185	present research findings in any official format
186	before reporting those research findings back to
187	firefighters, so as to ensure firefighters always
188	hear interpretable results first from scientists
189	and without any delay.
190	(j) Community Based Participatory Research
191	(CBPR) – CBPR is a collaborative approach to
192	research where scientists and firefighters
193	collaborate as equal partners on all aspects of a
194	research project including but not limited to:
195	developing research aims, study design/execution,
196	design of preventative interventions, and
197	dissemination of research findings in a
198	comprehensible format within an agreed upon
199	timeframe.
200	(k) "Helicopter Research" – The concept of
201	helicopter research is one where scientists drop
202	into the daily lives and operations of firefighters,
203	engage with them in often very personal ways
204	such as collecting blood and urine samples, and
205	then take off, never to be heard from again,
206	violating the principles of respect for persons,
207	beneficence, and justice.
208	(1) Scientists engaging in "helicopter research"
209	publish research papers and present at conferences
210	for their own professional benefit, while leaving a
211	sense of frustration and loss among firefighters

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212	when such scientists take what they need, but do
213	not share research findings.
214	(m) In order to ensure respect for persons,
215	beneficence, and justice, and to prevent
216	"helicopter research", IAFF locals
217	should refuse to participate in or endorse research
218	that does not utilize a CBPR approach.
219	(n) Helicopter research in any format is
220	unacceptable, and should be reported to the
221	General President of the IAFF and/or his
222	designee(s) in writing; and be it further
223	RESOLVED, That the GP will charge staff to
224	immediately begin the process of working through a
225	similar Bill of Rights for Canadian locals, given the
226	cross-border differences. That Bill of Rights will
227	come up at the 2026 convention for consideration,
228	along with any revisions to the US version, if needed.

Submitted by: Metro-Dade Firefighters, IAFF Local 1403 Los Angeles County Fire Fighters Local 1014 Cost Estimate: None Annual or Perpetual Designation: N/A

COMMITTEE RECOMMENDATION: Adopt as Revised CONVENTION ACTION: Adopted as Revised and Amended