Dear ______________:

We are writing to request [Name of hospital]’s participation in an important public health surveillance registry called CARES (Cardiac Arrest Registry to Enhance Survival). The CARES Program is a collaborative effort of the Centers for Disease Control and Prevention (CDC), the American Heart Association (AHA) and the Emory University School of Medicine, Department of Emergency Medicine, Section of Prehospital and Disaster Medicine, to help local communities identify and track cases of cardiac arrest and identify opportunities for improvement in the treatment of out-of-hospital cardiac arrest (OHCA). We have provided additional information about the CARES Program below and attempted to answer some of the questions you may have about your hospital’s participation.

CARES is a simple but powerful surveillance registry that can be used to identify and track all cases of OHCA in a defined geographic area by collecting a small number of key data elements from three sources – 911 Computer Assisted Dispatch, EMS units, and receiving hospitals – and linking them into a single report. CARES utilizes an internet database system that reduces time involved in registering events and tracking patient outcomes with hospitals. Multiple reporting features can be generated and monitored continuously through secure online access by CARES participants, which allows for confidential longitudinal, internal benchmarking.

EMS providers initiate each CARES report, which results in an automatic email notification to the receiving hospital, prompting them to log onto the HIPAA-compliant CARES website to provide data. Once logged into the CARES website, the hospital contact will have the necessary information to identify the patient and provide relevant outcomes data. The hospital dataset consists of five basic questions, which include emergency department outcome, hospital outcome, disposition location, hypothermia treatment if provided and neurological status at time of discharge. Each participating hospital can have confidential access to its own patient outcome data, but is restricted from viewing or accessing data provided by other participating hospitals, EMS providers and 911 dispatch agencies. Such secure restricted access and efforts to minimize the administrative burden in the data entry process are integral to allowing the surveillance registry to become sustainable in participating communities.

The disclosure and use of protected health information (PHI) in connection with CARES is permissible under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) under the regulation issued at 45 C.F.R. § 164.512(b)(1)(i). The regulation authorizes a public health authority to collect or receive PHI, without individual patient authorization, for the purpose of preventing or controlling disease, injury or disability, including the conduct of public health surveillance. The CDC and organizations acting under the CDC’s authority are considered public health authorities under the regulation. For your convenience, I have attached a copy of the letter from the CDC that reflects the CDC’s grant of authority to the Emory University School of Medicine to function as a public health authority under 45 CFR § 164.512(b) in carrying out the CARES Program.

Each institution’s IRB must make its own determination as to what type of review, if any, should be provided to the CARES Program. The Emory IRB has reviewed this study, and in particular
the CDC’s letter granting the Emory University School of Medicine to act on behalf of the CDC, as a public health authority, in collecting this information. In view of this letter, the Emory University IRB has determined that the CARES Program constitutes a public health activity and does not constitute “research” as defined under the regulations at 45 CFR Part 46 (“Common Rule”), and therefore does not require IRB review.

The ultimate goal of CARES is to help local EMS administrators and medical directors identify who is affected, when and where OHCA events occur, which elements of the treatment system are functioning properly and which elements are not, and how changes can be made to improve cardiac arrest outcomes. As more communities participate in CARES, confidential, external benchmarking can occur between similar EMS systems across the United States.

Please refer to the CARES website (https://mycares.net) for more information on the program. Do not hesitate to contact the CARES staff (cares@emory.edu) for additional information.

We look forward to implementing the CARES Program in the _______________ area, and we hope to hear from you soon.

Sincerely,

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