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POLICY FOR DISCLOSURE OF REPORTABLE DISEASE INFORMATION

Applies to:

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Division of Acute Disease Prevention and Emergency Response
Bureau of Immunization and Tuberculosis (ITB)
Bureau of Emergency Medical Services (EMS)
Center for Acute Disease Epidemiology (CADE)
Center for Disaster Operations and Response (CDOR)

Division of Environmental Health

Division of Behavioral Health
Bureau of HIV/AIDS, STD and Hepatitis

I. PURPOSE AND SCOPE OF POLICY

The Iowa Department of Public Health (IDPH) and local boards of health and health departments (including county, city, and district boards and departments) are governed by Iowa's Open Records law, and generally provide public access to all records they maintain. (Iowa Code chapter 22). In addition, IDPH and local boards of health and health departments are committed to providing information, data, and records to the public and the media to promote and protect the health of the population.

However, Iowa law also provides that certain information, data, and records maintained by IDPH and local boards of health and health departments are confidential and may not be disclosed to the public, including records received and maintained by IDPH and local boards of health and health departments as a part of their efforts to track reportable diseases and control communicable disease outbreaks. (Iowa Code §139A.3). The purpose of this policy is to outline the legal status of records containing reportable disease information, and to provide guidance to IDPH employees and to local boards of health and health departments regarding the disclosure of such information.

“Reportable disease” is defined in Iowa law as any disease or condition designated by IDPH as reportable, and includes over sixty diseases, conditions, and poisonings specifically named in administrative code. “Reportable disease” also includes any disease or condition that occurs in unusual numbers or circumstances, unusual syndromes, uncommon diseases, diseases and conditions suspected to be caused by a

deliberate act, and outbreaks of any kind. (641 Iowa Administrative Code (IAC) chapter 1, Appendices A & B). Reportable disease records include any written or electronic document that contains reportable disease information, and include but are not limited to initial case reports, follow-up case investigations, information obtained during cluster and outbreak investigations (including e-mail based surveys like Survey Monkey), and medical records.

II. IDENTIFIABLE INFORMATION IS CONFIDENTIAL

As a general rule, reportable disease records and other information which identifies a person or business involved in a reportable disease investigation are confidential under Iowa law. The law specifically provides as follows:

A report or other information provided to or maintained by the department, a local board, or a local department which identifies a person infected with or exposed to a reportable or other disease or health condition (or a business associated with a reportable or other disease or health condition) is confidential and shall not be accessible to the public.

Information contained in a report may be reported in public health records in a manner which **prevents** the identification of any person or business named in the report.

“Business” includes entities with identifiable proper names, such as schools, churches, non-profit organizations, restaurants, and companies.

(Iowa Code § 139A.3(2)“b” & “c”; see also Iowa Code §§ 22.7(2), 22.7(16), 139A.30, 641 IAC 1.17(1)). This section includes information about persons who have been diagnosed through positive test results or other means, and also includes information about persons for whom IDPH or local boards of health or health departments maintain pending or negative test results.

Information which identifies a business named in a report is also confidential and shall not be accessible to the public. (Iowa Code § 139A.3(2)“c” and 641 IAC 1.17(2)). “Business” is defined broadly in the law as “every trade, occupation, or profession.” (Iowa Code § 139A.2(2)). The identity of a business may be released in certain **limited** circumstances discussed in section IV of this policy.

Identifiable information (or identifiers) includes information that can be used to directly establish the identity of a person or business, such as a name, address, or unique identifying number. Identifiable information also includes information that can be used to indirectly establish the identity of a person or business by linking such information or data with external information that allows for identification of the person or business, such as obituaries, newspaper articles, or information on public websites.

III. STATISTICAL, AGGREGATE OR TABULAR DATA MAY BE RELEASED IN ACCORDANCE WITH THE FOLLOWING GUIDELINES

Information contained in a disease report may be reported in public health records or otherwise released by IDPH or local boards of health or health departments only “in a manner which prevents the identification of any person or business named in the report.” (Iowa Code § 139A.3(2)“c”; see also §139A.30). This provision authorizes IDPH and local boards of health and health departments to release disease information to the public so long as such release does not result in the identification of a person or business. IDPH and local boards of health and health departments may therefore generally release information or data in an aggregate or a tabular format.

The determination of whether the release of aggregate information or tabular data would result in the identification of a person or business may be straightforward -- for example, IDPH *can* clearly report that the state experienced 1,066 cases of pertussis in 2008 without violating confidentiality provisions. Likewise, IDPH clearly *cannot* report that a 39 year old African American male residing in Page County is infected with Lyme disease if there is only one 39 year old African American male residing in Page County, as such release would result in identification of this individual. Oftentimes, however, the determination of whether the release of information is consistent with confidentiality restrictions is more complex and may require additional analysis and consultation with these guidelines and the department’s legal counsel and medical advisors.

In determining whether release of aggregate information or tabular data would result in the identification of a person or business, IDPH will generally follow the Centers for Disease Control and Prevention’s (CDC) scientifically acceptable principles for confidentiality protection. Specifically, IDPH has relied upon selected guidelines from the CDC’s Staff Manual on Confidentiality, the National Center for Health Statistics Staff Manual on Confidentiality, and the CDC-CSTE Intergovernmental Data Release Guidelines Working Group Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-Release of State-Provided Data, in preparing this policy. In addition, IDPH relied in part upon the Washington State Health Department’s Guidelines for Working with Small Numbers in developing this policy. These sources can be found on agency specific web-sites.

In general, the following guidelines apply to the release of reportable disease information by IDPH and local boards of health and health departments:

Disclosure of Personal Identifiers Prohibited.

- IDPH and local boards and health departments shall not release information which directly identifies a person or business named in a reportable disease report, including name, address, telephone number, social security number, medical record number, exact date of subject’s birth, or other direct identifiers.

Example: On January 1, 2009, a physician reports to the Johnson County Health Department and IDPH that Jane Doe, medical record number 7654321, a female living at 100 Main Street in Iowa City, Iowa, has Salmonellosis. Jane Doe's name, medical record number, and address are confidential and cannot be released by either health department. However, her case will be added to the total number of Salmonellosis cases in Johnson County and the state for the year, and that total number may be released.

Example: The Polk County Health Department is informed that Capitol City Restaurant has a cook named Jane Doe with Hepatitis B, a disease that is not transmissible in food or in a restaurant setting. Both the patient identifying information and the restaurant name are confidential and cannot be released to the public.

- IDPH and local boards of health and health departments shall not knowingly release information which can be used to indirectly establish the identity of a person or business named in a disease report by the linking of the released information or data with external information which allows for identification of such person or business.

Example: John Doe, an 87 year old man from Dickinson County, dies of West Nile Virus on August 1, 2010. An obituary in the local paper states his age at death and the date of his death. If IDPH releases information that an 87 year old man from Dickinson County died on August 1st from West Nile, that information could easily be linked with the obituary to establish his identity and that he was infected with this disease. For this reason IDPH and local boards of health and health departments should not release all of these specific identifiers about John Doe, but instead should broaden one or more of the identifiers to prevent the identification of John Doe. See how to broaden identifiers below.

Certain media outlets have expressed an interest in receiving information about (1) county of residence, (2) age range in the general categories of child, young adult, adult, or elderly, (3) time frame identifier, and (4) health status. In some cases it will be appropriate to release information from all four categories as requested. Again, however, one or more identifiers may need to be broadened to ensure that the information provided cannot be linked with external information to allow for identification of such person or business – for example, county of residence could be broadened so that the release provides that an elderly person in northwest Iowa died of West Nile on August 1, 2010; or the time frame identified could be broadened, so that the release provides that an elderly person from Dickinson County died of West Nile in August of 2010. **See section VI concerning release of data to the media.**

Example: A seven year old black male in Taylor County has sickle cell anemia. This type of anemia is most commonly found in African-Americans. Since there are few African Americans in Taylor County, IDPH

and local boards of health and health departments should not publicly disclose that a seven year old in Taylor County has sickle cell anemia, as doing so could lead to the identification of the child.

- IDPH and local boards of health and health departments shall not respond to inquiries which include direct personal identifiers in a manner which confirms an inquiry.

Example: *IDPH stated in a press release that Toxic Shock syndrome caused the death of an Iowa adult in Winneshiek County in the month of August 2009. If a reporter asks whether Mary Smith was the woman in question, IDPH cannot confirm or deny the identity of the individual, as doing so would result in IDPH disclosing confidential information. In addition, if a member of the public asks for the final IDPH report of the outbreak investigation involving Mary Smith, IDPH may not respond to such inquiry as doing so would confirm that Mary Smith was the subject involved. IDPH may suggest that the public records request be broadened so that IDPH is not in jeopardy of revealing confidential information – for example, suggest that the request be made for all final public IDPH outbreak reports for the year 2009.*

Example: *An employer contacts IDPH concerned about the health status of their employee Jane Smith, when told that this is confidential information, he then asks whether his business has an employee infected with Hepatitis C. IDPH cannot release any information about the health status of any individual employee to the employer, nor that any employee has been tested (regardless of whether the test results are negative or positive).*

Example: *Little Johnny Doe goes to River City Elementary School, and develops pertussis. A local reporter calls and wants to know what school Johnny attends. IDPH and local boards of health and health departments cannot disclose any information that would confirm that Johnny has pertussis, nor can public health generally disclose the school involved in the pertussis outbreak.*

Aggregate Data Values.

- When releasing reportable disease information or data to the public, IDPH and local boards of health and health departments should expand or broaden the identifier fields as needed in order to prevent identification. Common methods for preventing identification include:
 - Redacting (removing) variables which directly identify a person or business, including name, address, telephone number, social security number, medical record number, exact date of case-patient's birth, or other direct identifiers.

- Collapsing continuous/interval data (ex: age, date of occurrence) into broad categories.
- Collapsing ordinal data (ex: location, geography) into broad categories.
- Suppressing of small numbers to ensure confidentiality

Use Numerator/Cell Size Rules for Data Aggregation or Suppression.

- When releasing reportable disease information or data to the public, IDPH and local boards of health and health departments should use numerator/cell size rules to either guide selection of groupings of aggregated data values, or if aggregation is insufficient, to suppress release of certain cells in a table. **IDPH and local boards of health and health departments should not release data if the numerator cell size is three or less: numerator cell size counts of one, two, and three should not generally be disclosed.** A count of no cases or events in the cell is not a threat to confidentiality and may be released, but a count of one, two, or three cases or events is a threat to confidentiality and should not be released.

Definitions:

A numerator is the number on top and a denominator is the number on the bottom of a ratio. For example, if 13 of 62 people who attended a church supper became ill, 13 is the numerator, and 62 is the denominator.

A line listing is a row of data in which only one piece of information per category is available. For example, the number of cases per county is available in the line listing of reportable diseases in Iowa. (See example at www.idph.state.ia.us/adper/common/pdf/cade/decades.pdf).

Example:

	Polk	Story	Linn	Hamilton	Adair	Adams
<i>Salmonella</i> cases	117	51	42	8	2	1

A table refers to the arrangement of descriptive or identifying data (for example age, sex, or race) in columns (vertical) and lines (horizontal), with the intersection of a column and a line referred to as a “cell”, where several pieces of information are available per number. For example, the following hypothetical table of *Salmonella* cases in Polk County includes age and race. This sometimes referred to as “cross-tabs” when two pieces of identifying information (e.g., age and race) are used to arrange data in a table.

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	Total
White	22	16	13	11	10	72
Black	11	6	4	6	8	35
Asian	2	1	2	1	3	9
Pacific Islander	0	0	0	0	1	1
Total	35	23	19	18	22	117

Example: The suppressed version of the table above as it can be released to the public. (This assumes that there are more than 300 Asian/Pacific Islanders that are over age 80 in Polk County. If there were less than 300, consider combining the age 61-80 and age 81+ to ensure that the denominator was large enough.)

Salmonella Cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	Total
White	22	16	13	11	10	72
Black	11	6	4	6	8	35
Asian / Pacific Islander	S	S	S	S	4	10
Total	S	S	S	S	22	117

S= suppressed number

Example: A local health department is asked for information about pertussis by age and gender. The county has had two 3 year old males, two 4 year old males, and one 5 year old male with pertussis. Because there are less than 3 in each cell, the county should collapse the individual ages into one cell of children five years of age and under, so the release of information would state the county has had five males 5 years of age or younger with pertussis.

If data is released in table format, the following additional guidance should be followed:

- In no table should all cases of any line or column be found in a single cell.
- In no table should the total figure for a line or column of a cross-tabulation be three or less.
- In no table should it be possible to identify a person or business through subtraction or other calculation from the table or a combination of tables.
- Data released by IDPH or local boards of health and health departments should not permit identification of a person or business when used in combination with other external data.

Use Denominator/Population Size Rules for Data Aggregation or Suppression.

- When releasing reportable disease information and data, IDPH and local boards of health and health departments should use denominator/population size rules to either guide selection of groupings of aggregated data values, or if aggregation is

insufficient, to suppress release of certain cells in a table. Prior to disseminating reportable disease information, IDPH and local boards of health and health departments should consider the size of the denominator (the population size represented in each cell of a table). Data should not be released if the total population from which the data are drawn is less than a certain size, based on the premise of a size sufficiently large enough that no subcell of the variables contained in the data would be expected to be smaller than a certain size. Generally, tabular data based on denominations greater than 300 persons per cell present *minimal* risk for personal identification. Caution should be exercised if the cell's population size is between 100 and 300, and release should not occur if the population is less than 100.

Example: Assume there is an outbreak of Giardiasis in Ayrshire, Iowa, population 202, where four ten year old's were infected with this disease. Public health authorities should not release that four ten year old children in Ayrshire were infected with Giardia, because even though the numerator/cell size is over three, the denominator/population size is below 300. Because there is only a small number of ten year old children in this town, such release may in effect be identifying every one of these children as infected with Giardia. The release should instead provide the relevant information for the county.

Summary

- IDPH and local boards of health and health departments shall not release information which directly identifies a person or business named in a reportable disease report, nor respond to inquiries in a manner that confirms the identity of a person or business.
- IDPH and local boards of health and health departments should generally not report cells with counts of three or less.
- IDPH and local boards of health and health departments should be cautious when reporting rates or ratios based on denominators less than 300 and should not disclose data based on denominators less than 100.
- IDPH and local boards of health and health departments should be cautious when reporting a specific disease in a minority population if a high proportion of the minority population has this disease, or if the disease is primarily found in a specific population.
- When producing tables, IDPH and local boards of health and health departments should be careful that users cannot derive confidential information through a process of subtraction.

IV. IDENTITY OF BUSINESS MAY BE RELEASED UNDER LIMITED CIRCUMSTANCES

Information concerning the identity of a business involved in a disease investigation may be released to the public when the State Epidemiologist or the Director of IDPH determines such a release of information necessary for the protection of the public. (Iowa Code § 139A.3(2)"c"). In these limited circumstances, efforts should be made to actively involve the business in the release of the information to mitigate damages to the reputation of the business to the extent feasible.

***Example:** IDPH receives a report that a salad maker at a fast food restaurant in Ankeny is infected with Hepatitis A. The fast food restaurant accepts cash only, so there is no reliable method to trace and warn its customers. The State Epidemiologist determines that it is necessary for the protection of the public to release the name of the restaurant so that individuals who have eaten at the restaurant are aware that they may have been exposed to this disease, and may wish to get vaccinated. IDPH could appropriately issue a press release with the restaurant name and times of potential exposure. IDPH should make an effort to involve the restaurant in the press release and any media appearances and to discuss efforts the restaurant has undertaken to ensure that no customers become ill.*

Prior to releasing the name of a business, local boards of health and health departments **must** obtain a determination from the State Epidemiologist or the Director of IDPH that such a release is necessary to protect the public. Local boards of health and health departments and officials are not authorized under law to make such a determination independently. IDPH will typically consult with legal counsel prior to reaching this determination to ensure that the release of information is appropriate from a legal and a public health perspective.

Recalls

If a federal regulatory agency announces a recall of a particular product, the State Epidemiologist automatically deems a release of the name of any business identified in the recall as necessary for the protection of the public. Hence IDPH and local boards of health and health departments may refer to the proper name of the business identified in a federal recall announcement in any public release of information about the investigation. However, information which identified any person involved in such recall or investigation remains confidential.

V. HIV/AIDS INFORMATION

IDPH and local boards of health and health departments collect and maintain reports regarding individuals infected with AIDS-related conditions, including HIV. (Iowa Code §§ 139A.3, 141A.6, and 641 IAC 1.3). HIV and AIDS information is subject to stricter confidentiality protections under both federal and state law than other reportable

disease information maintained by IDPH and local boards of health and health departments. (Iowa Code § 141A.9, 42 CFR part 2). The law related to HIV/AIDS information does, however, authorize release of “medical or epidemiological information for statistical purposes in a manner such that no individual person can be identified.” (Iowa Code § 141A.9(1)“g”). IDPH and local boards of health and health departments should follow this policy in determining whether a release of information for statistical purposes prevents identification of individual persons.

VI. RELEASE OF DATA TO THE MEDIA

An important mission of public health is informing the public through the media about issues which impact the public’s health. IDPH and local boards of health and health departments should collaborate with their public information officers or other appropriate staff to determine the content, nature, and scope of information to be released to the media.

When releasing demographic information regarding specific case-patients to the media, the following guidelines should generally be followed. In certain situations this level of detail may not be appropriate for release as described in this policy, and if there is a question about the specificity of information which should be disclosed consultation should be sought from legal counsel prior to release of the information.

Age Range:

The following age ranges should generally be used to report both illnesses and deaths. In press releases, the age ranges should be included in parenthesis within the text as demonstrated below.

- Child (0-17 years of age)
- Adult (18-40 years of age)
- Middle age (41-60 years of age)
- Older Adult (61-80 years of age)
- Elderly (81+ years of age)

Gender: The gender of the case patient should generally be released.

Geographic information: The smallest geographical area as appropriate should generally be released.

- 1) County (release name of county of residence)
- 2) Region - five regions will be used for the state:
 - a. Northeast (NE)
 - b. Southeast (SE)
 - c. Central
 - d. Northwest (NW)
 - e. Southwest (SW)
- 3) State (as a whole)

Ethnic and Race: The ethnicity and race of a patient will not generally be disclosed in a press release.

Example: *A 3 year old girl from Clay County dies of H1N1 influenza and her obituary is published in the local paper and on the local funeral home’s website. Because an obituary is in the public domain, children deaths are rare, and Clay County has a relatively small population, the following would generally be appropriate for release – “a female child (0-17 years of age) in Northwest Iowa died of H1N1”.*

Example: *A 63 year old man in Scott County becomes ill from Lyme disease but does not die. Because he did not die there is not information in the public domain about his illness. In addition, illness in people of this age is not rare and Scott County has a relatively large population – hence the following would generally be appropriate for release – “an older adult (61-80 years of age) male Iowan in Scott County became ill with Lyme disease”.*

In unusual situations, or when unexpected information is in the public domain, the above standardized guidelines may need to be modified. These modifications should be consistent with other sections of these guidelines and consultation with public information officers and legal counsel may be appropriate.

VII. LIMITED EXCEPTIONS WHICH AUTHORIZE RELEASE OF PERSONALLY IDENTIFIABLE INFORMATION

In addition to those disclosures of information authorized above, Iowa law also allows IDPH to disclose reportable disease information under the following circumstances:

- Reportable disease records and information may be shared by and between IDPH employees and local board of health and health department employees who have a need for the information in the performance of their duties. (Iowa Code § 139A.3, 641 IAC 175.10(2)“a” & “e”, 641 IAC 1.17(3)“a” & “b”). Hence, IDPH and local health department employees may share any information necessary to effectively conduct a disease investigation.
- Reportable disease records and information may be shared with public health departments in other states or the CDC or other federal agencies when necessary for the other entity to perform their duties or as necessary to conduct the investigation. (641 IAC 175.10(2)“e”, 641 IAC 1.17(3)“d”). Confidential information provided to other departments retains its confidential status and shall not be re-released by the receiving entity. In general, however, CDC and other federal agencies do not receive or retain individual identifying information.

Example: An Illinois resident is hospitalized in Davenport Iowa, and is reported to Iowa public health officials as being ill with Lyme disease. This information, including name, address, and phone number of the resident, may be shared with Illinois public health officials (both the state and the case's local health department) as this information is needed by them to conduct the investigation and perform their job duties.

Example: Investigators from the CDC are in Iowa assisting in an investigation of a reportable disease (children attending a day care center with high levels of lead poisoning). As part of the investigation, the CDC investigators have access to the names and other identifying information of these children; however, this information is confidential. When the investigators return to CDC, all identifying information should be redacted from any records or copies of records they remove from the state. Instead, for example, identification (ID) numbers could be given to each child, and a log made linking the ID numbers to the children's names. Any information leaving the state would only have the ID numbers on them and the log would be maintained by the Iowa public health officials. The day care center could be referred to as "day care center A" in all documents, and the proper name redacted.

- Reportable disease records and information may be shared with other state governmental entities when necessary for those entities to perform their job duties. However, this information must be kept confidential by the receiving agency. (641 IAC 175.10(2)"d" & "e", 641 IAC 1.17(3)"d").

Example: IDPH staff investigating an outbreak Q Fever may share information with the Iowa Department of Agriculture and Land Stewardship (IDALS) as necessary for both agencies to conduct their respective investigations. However, IDALS would be required to maintain the confidentiality of this information.

- Reportable disease records and information may be shared by and between IDPH and local public health employees and health care providers, hospitals, and laboratories, as necessary to effectively conduct an investigation and to provide appropriate medical care. (Iowa Code § 139A.3, 641 IAC 1.4, 641 IAC 1.17(3)"c")
- Reportable disease records may be released to the subject of the record (the individual who became ill) upon receipt of a written authorization for release from the subject or the subject's legal representative. (641 Iowa Administrative Code 175.12). IDPH should exercise caution to ensure that other confidential information (i.e. reference to other ill individuals or involved businesses) contained in the report is redacted prior to release to the subject.
- Reportable disease records may be released in response to a court order or subpoena. (641 IAC 175.9(2)"g"). Review shall be performed by the IDPH's legal counsel or local board of health and health department's legal counsel prior to release.

- Reportable disease information may be included in a quarantine or isolation order or site placard as necessary to prevent the spread of a quarantinable disease. (Iowa Code § 139A.4, 139A.5, 641 IAC 1.9, 641 IAC 1.17(3)"e"). Public health officials should exercise caution prior to posting such placards, and consult with IDPH's legal counsel or the local board of health and health department's legal counsel prior to taking action.
- IDPH may share personally identifiable information regarding diseases, health conditions, unusual clusters, or suspicious events that may be the cause of a public health disaster with the department of public safety, the homeland security and emergency management division of the department of public defense, and other appropriate federal, state, and local agencies and officials. (Iowa Code § 135.145(2)). The sharing of such information must be restricted to only that information necessary to prevent, control, and investigate the public health disaster. (Iowa Code § 135.145(3)).
- Personally identifiable information regarding AIDS/HIV may be released only in the limited circumstances authorized by Iowa Code section 141A.9.

VIII. PENALTIES FOR UNAUTHORIZED RELEASE OF INFORMATION

A person who knowingly violates the confidentiality statutes and administrative rules cited above may be subject to criminal prosecution for a simple misdemeanor and may be subject to disciplinary action under IDPH or the relevant county's personnel policies, up to and including discharge from employment. A person who releases HIV/AIDS information is subject to criminal prosecution for an aggravated misdemeanor and is subject to civil action and civil penalties, and may be subject to disciplinary action under IDPH or the relevant county's personnel policies, up to and including discharge from employment. (Iowa Code §§ 139A.25, 141A.11).

In addition, while IDPH is not a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), local boards of health and health departments generally are covered entities, and may therefore be subject to an enforcement action under HIPAA if the local board of health or health department releases protected health information in violation of that regulation. Local boards of health and health departments should seek advice from their legal counsel to ensure their compliance with the federal law.

Hospitals, health care providers, and other covered entities are not precluded by HIPAA from sharing reportable disease information with public health authorities or from participating in disease outbreak investigations and such entities must under state law provide this information to IDPH and local boards of health and health departments. (Iowa Code chapter 139A, 641 IAC chapter 1; 45 CFR 160.203; 45 CFR 164.512(a); 45 CFR 164.512(b)(1)(i)).

IX. QUESTIONS REGARDING APPLICATION OF THE GUIDELINES

Questions regarding application of these guidelines in specific circumstances may be directed to the following individuals:

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