CHAPTER 8

Family Coordination and Liaison

Working with the families of victims of a mass fatality incident is likely to be foreign to most DNA laboratories. This chapter discusses the formation of a family assistance center and a family hotline and discusses a number of helpful forms, including the most recent version (in English and in Spanish; see appendix G) of the brochure on the DNA identification process that was distributed to victims' families shortly after the 9/11 attacks.

A laboratory's response to a mass fatality incident is a departure from normal criminal casework in which DNA testing generally is conducted on behalf of the State (or the defense)—with a law enforcement agency acting as the buffer between the laboratory and the victim or the victim's family. In a mass disaster DNA identification effort, however, the laboratory becomes a gateway, rather than a buffer—with the laboratory working directly with families to collect information about victims and reference samples.

Consequently, the laboratory and victims' families often share a close, albeit short-term, relationship. Families become temporary stakeholders in the laboratory's performance because many decisions made during a mass fatality incident response affect them profoundly. For example, the minimum fragment size and "when are we finished" decisions (see chapter 4, *Major Decisions*) determine how much of, and in what condition, a loved one's remains will be received by the family.

Depending on the extent to which the victims' families are organized, they may have a strong voice in shaping nonscientific decisions. The laboratory also may receive, via elected officials, complaints from victims' families. The best advice in these situations is that common sense should prevail. The needs of the families of victims of a mass fatality incident are, first and foremost, to have their loved ones identified and buried. Each family needs an official death certificate to settle their loved one's estate and collect any life insurance benefits.

Finally, families want information. Most laypeople do not understand forensic identification modalities, and DNA can seem especially mysterious. Often, families do not know why they are being asked to provide their loved one's personal items or why the laboratory is requesting DNA samples from relatives. They may not understand the difference between a biological relative and someone who is called "aunt," for example, but is not actually related. Laboratory directors would be well advised to develop a policy for dealing with a nonrelative who wants to provide a kinship sample. Being able to "do something" is a natural part of the grieving process, and the laboratory can always discard the sample. However, since this may raise false hopes, it may be best to consult with a bioethicist before developing a policy.

Some families may be concerned at what they perceive as the government asking questions about their DNA or their relationship to a mass fatality incident victim. Also, once DNA samples are provided, families may not hear anything for days, weeks, or even months, which can cause additional anxiety about the government's use of their DNA. The entire process can be bewildering and frustrating to the families of victims, which is even more reason for a laboratory's policies regarding sample disposition, privacy, and other personal information concerns to be communicated clearly and respectfully.

The Family-Laboratory Relationship

The relationship between the laboratory and the victims' families can be greatly affected by the duration of the identification effort. Lengthy mass fatality incident responses require greater interaction between the laboratory and the families. Families will look to the laboratory to provide regular updates and explain why the process may seem as if it is taking so long. In DNA identification efforts that last an appreciable time, as was the case after the World Trade Center (WTC) attacks, families may organize to more effectively convey their needs to policymakers and other decisionmakers.

> **There were several family groups that formed after the 9/11 attacks. The largest, Give Your Voice, was started by a single family; the firefighters had a large family group; there was a family group in Boston and one on Staten Island. We made it a point to present the DNA story to these groups, and to answer their questions when they arose.**
>
> ***Robert Shaler***

When a single business entity is involved in a mass fatality incident (e.g., an airline company in the case of an airline disaster), the company usually establishes a family assistance center, which serves as a bridge between the ME and the victims' families. Where there is no single corporate affiliation, however, as in the case of the WTC attacks, the government may establish an entity equivalent to a family assistance center to serve as an intermediary. Family assistance centers may coordinate the collection of victim and kinship information and reference samples. In cases involving victims from foreign countries, the laboratory may have to work directly with foreign consulates.

Family assistance centers also play a role in communicating the status of the identification effort to the families. Confusion can be reduced when a family assistance representative is brought directly into the ME's or laboratory's organizational structure and receives the same briefings as the laboratory staff, as well as additional tutorials on how DNA testing works. The family assistance representative can then coordinate with other family assistance personnel to better aid the families, thus allowing the laboratory to focus on analyses and identification. This type of collaboration between the family assistance center and the laboratory can improve and expedite the identification process and is most feasible when the family assistance center is established by an official agency rather than an ad hoc emergency group. Exhibit 13 shows the relationships between the laboratory and the victims' families.

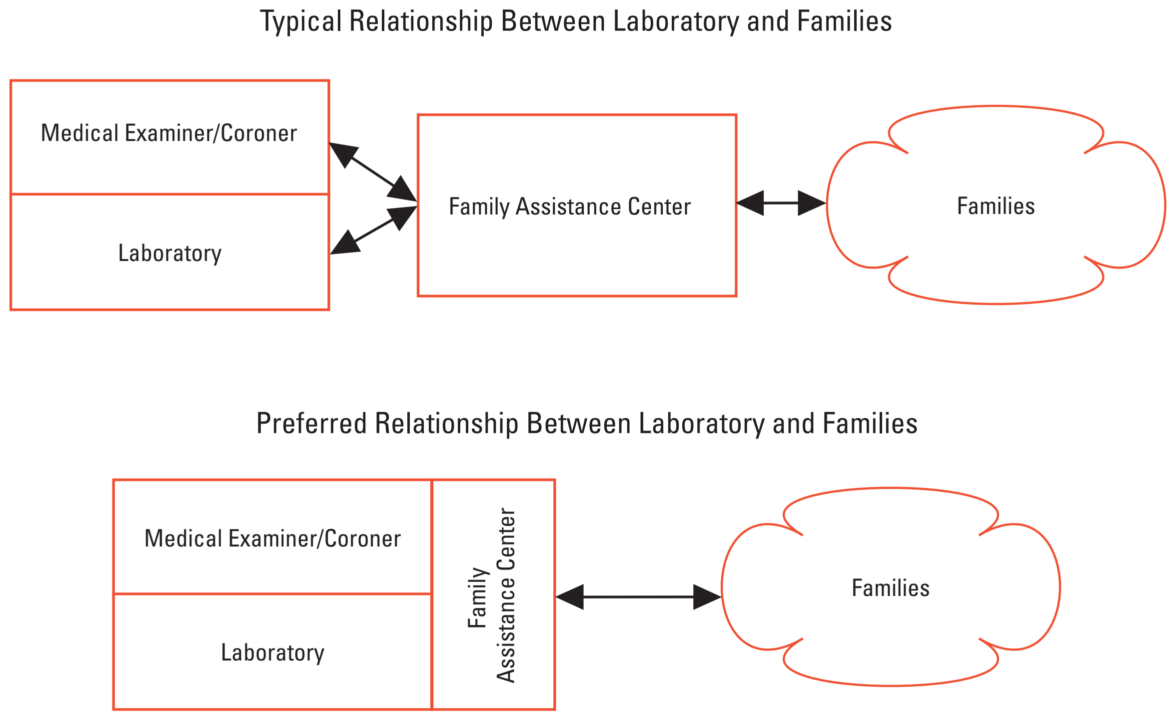
Collecting Reference Samples

The Victim Identification Program (VIP) is software developed by the Disaster Mortuary Operational Response Teams (DMORT), a program of the U.S. Department of Homeland Security, to collect victim information. VIP contains approximately seven pages of victim-related data, tailored for making mass fatality incident identifications. This information (primarily non-DNA-related) is gathered by DMORT personnel or collection center officials through interviews with the victims' families. Although the families generally complete the printed VIP forms with the aid of family assistance centers, it is possible for the process—if well organized and well financed—to be done via computers.

Currently, there are no standards that govern the collection of reference samples (i.e., personal items and kinship samples) from families. Historically, DNA laboratories have designed forms used in the collection process on an ad hoc basis—and, in some situations, forms have been designed on-the-fly, hours before they have been put into use. Appendixes B and C to this report (a sample Personal Items Submission Form and a sample Family and/or Donor Reference Collection Form) may be helpful. It may be important to also keep in mind:

- Family members are under extreme stress in the days following a mass fatality incident, and their minds may be elsewhere during the collection process, causing them to inadvertently provide incorrect information. To avoid such mistakes, collection forms should be as simple as possible.
- Every reference sample form should contain the following information about the victim:
  - Full name, including whether they are a Junior, Senior, etc.
  - Date of birth.
  - Social Security number (if known).

Exhibit 13: Relationship Between Laboratory and Victims' Families



It is not uncommon for several victims in a large disaster to share the same name but be unrelated. Similarly, related individuals with the same names—cousins, for example—may be victims in a single event. Consistent use of the following guidelines will ensure that the proper reference samples are assigned to each victim:

- Always collect the donor's full name and date of birth. During times of grief, relatives may not realize that they are using nicknames or that a father's "Bob" may be a mother's "Robby."
- Europeans and Americans write dates differently (the standard European notation is DD/MM/YY). Ensure that month and day fields are unambiguous on collection forms.
- Family members frequently transpose their relationship to the victim. In most cases, this is a result of a poorly worded question such as, "What is your relationship to the victim?" It is better to ask questions from the perspective of the donor. For example, "The victim is my ___________." or "I am the victim's ___________." Also, the dates of birth of the donor and the victim can be used to help correct these mistakes.
- Collect as much information as possible about the relevant family structure; the sample form found in appendix C may be a helpful guide. The laboratory can compare purported pedigrees from members of the same family, then use dates of birth and genotypes to help discern the true relationships.
- Collect as much information and as many samples as possible. There may not be another opportunity.

Generally, collection centers are staffed by members of the family assistance center, DMORT, and ME personnel. It is critical that the laboratory staff participate in the reference sample collection process, and it is advisable for the laboratory to define and control the process. Non-DNA laboratory personnel usually do not have the expertise to assess how kinship samples or personal items will contribute to the DNA identification effort. For example, a family member might ask, "I have a

During the World Trade Center (WTC) DNA identification project, a software program that estimates whether a specific kinship sample will benefit the identification was explored. For example, suppose buccal swabs have been collected from a victim's father and sister. Will collecting DNA from the victim's grandson help meet the statistical threshold for making an identification? Charles H. Brenner, Ph.D., developed such a program to assist in the WTC identification efforts (see http://dna-view.com/simulate.htm).

second cousin living overseas; should we contact her for a sample?" Individuals trained in DNA analysis and genetics must be available to respond to such questions and ensure that the most valuable samples (from a DNA identification perspective) are collected and analyzed.

Traditionally, the metadata associated with a reference sample are collected on paper, then transferred to computer. Ideally, however, all information is entered directly into a database during the collection process. This helps reduce transcription and other data entry errors, such as those resulting from illegible handwriting. It would helpful, for example, if a specialized collection workstation could be constructed to streamline the collection procedure and guarantee greater accuracy. Features of a specialized collection workstation—many which are included in the software that the Armed Forces DNA Identification Laboratory (AFDIL) uses to collect reference samples—might include:

- Two monitors, one oriented toward the individual performing the data entry, the other oriented toward the family member (allowing the family member to validate information as it is entered).
- A device that electronically captures the donor's signature; these devices are already in use in some retail stores.
- A printer for creating copies of forms to be given to the donor at the end of the interview.
- A barcode printer; for example, buccal swabs and personal items could be immediately barcoded for the laboratory's sample tracking system.
- A digital camera to photograph personal items.

Two approaches may be used to collect reference samples from families: an "open house" (family members visit the collection center without an appointment during the day) and, the preferred approach, scheduled appointments when all family members are able to attend.

The primary advantage of the open house approach is that family members can come and go according to their own schedules. However, an open house has drawbacks, including:

- The collection site must be staffed, even when there is low or no demand.
- It can become chaotic if many people arrive at the same time (e.g., lunch hour, after work).
- Because members of the same family may arrive at different times, it can be difficult to ensure that specific personal items and kinship samples are assigned to the proper victim. This can occur, for example, if one family is mistakenly assigned more than one case number. (Note: Each victim should be assigned a unique case number. See chapter 9, *Information Technology*.)
- There is a greater probability that family members will provide conflicting pedigree information.

The preferred approach to collecting reference samples, however, is to schedule an appointment with an entire family unit. The primary advantage with this approach is that all the reference samples for a victim are collected at one time. Although each collection will take more time when an entire family is present, this approach decreases the chance of a sample mixup, allows the entire family to validate the pedigree, and uses laboratory staff time more efficiently.

Regardless of the collection approach, there invariably are some family members who—due to poor health or distance, for example—are unable to visit the collection center. In these cases, the collection center must make special arrangements to visit their homes, have other agencies (such as law enforcement agencies or phlebotomists) collect samples, or mail collection kits directly to family members. (Note: This last method circumvents appropriate chain-of-custody procedures and should not be used if strict forensic protocols are in force.)

As discussed in chapter 2, *How DNA Is Used to Make Identifications,* the number of possible identifications depends on the condition of the human remains and the reference samples. After the laboratory develops DNA profiles for all of the personal items and kinship swabs, it will assess whether the reference samples provide sufficient information to identify the victim. In some cases, the laboratory may need additional information from biological relatives or personal items.

Family-Laboratory Communications

If directed to do so by the ME, the laboratory director may have to keep family members apprised of the identification effort, including any challenges that might hinder making identifications. The relationship between the victims' families and the laboratory is a delicate one, and the laboratory should be prepared to clarify any incomplete or incorrect information and to do everything possible to educate the families.

One way to educate the victims' families—and the public, in general—is to provide basic information on how DNA is used in mass fatality incidents. In an effort to educate families of the WTC victims, for example, the National Human Genome Research Institute at the National Institutes of Health and the National Institute of Justice at the U.S. Department of Justice created a brochure, that describes the DNA identification process, including why reference samples are collected and how they are used. Appendix G to this report is the most recent version—in English and Spanish—of the brochure.

The WTC response also had a toll-free "family hotline" to supplement the work of the family assistance center. The hotline was staffed primarily by medical and legal investigators who were fluent in English and Spanish. DNA laboratory personnel also were brought in to offer advice on kinship samples and pedigrees. The hotline became the primary way that family members were able to find out if their samples produced usable DNA profiles and, if necessary, to schedule an appointment to bring in additional reference samples.

The families of WTC victims relied on the hotline to ensure they had done everything they could to help their loved one be identified. If a hotline is established, it would be important to have appropriate multilingual responders. DNA personnel should also be available to provide guidance on questions such as whether it would be helpful for a certain family member to provide a kinship sample.

Individuals staffing the hotline should have online access to:

- A log of contacts for each family, including who provided a reference or kinship sample and the date thereof.
- The victim's information (e.g., the data collected in the Victim Identification Program (VIP)).
- Chain-of-custody information for reference samples, including the type of sample, when it was received, who donated it, etc.
- The status of each reference sample submitted by the family, including whether its analysis yielded a useful DNA profile or when it is scheduled to be analyzed.
- Whether the amount of reference material is sufficient to make an identification.

It may be useful to assign particular individuals to work with particular families. Limiting the number of people with whom a victim's family has to deal may facilitate communication, build trust, reduce stress on the family, and limit unrealistic expectations. Of course, the feasibility of this approach will depend on the size of the mass fatality incident and whether staff is available to support a hotline.

A lesson we learned in the World Trade Center identification effort was that collection of the kin reference sample had to be appropriately placed in their genetic context at the time they were collected or there could be great difficulty later on in the analyses of identification probabilities. Therefore, geneticists and genetic counselors should assist with collected family relationship data from those contributing reference samples in the aftermath of a mass casualty disaster.

Joan Bailey-Wilson

The family brochure made it possible for the families of 9/11 victims to receive reliable information about the DNA testing process, including what they could expect and the meaning of results. The document also has been used to help families of missing persons, including after Hurricane Katrina.

Lisa Forman

Depending on the duration of the response, families may form their own groups. The laboratory or a designee may be asked to participate in family group meetings. This is an opportunity to provide information and dispel rumors or misconceptions about the DNA testing processes and results. For example, phrases used by a DNA professional may be incorrectly interpreted by a layperson. The term "intact body" is likely to mean one thing to a professional and another to a victim's loved one. The laboratory director also should be aware that several groups representing the families may exist and should not assume that all family members receive information that is imparted at these meetings.

For the families of missing persons, including the victims of the 9/11 terrorist attacks, there is no such thing as 'closure' or 'moving on.' Families first must do the hard work of grieving to get to a place where they intellectually accept that their loved one is gone; then they can learn how to forever hold them in their hearts. For many, the identification of remains helps them to get through the first part of this process so that they can do the harder work of the second part.

Leslie Beisecker

Sometimes, it may be helpful for family members to tour the laboratory and ME facilities to more fully understand the identification processes. With respect to DNA analysis, for example, family members are likely to inquire about the status of samples they provided, whether those samples provided usable DNA profiles, and whether they can do anything else to assist the effort. The laboratory should be prepared to answer these questions.

Finally, here are some additional lessons learned during the 9/11 DNA identification effort:

- Some people hold negative perceptions of civil servants, leading them to believe, for example, that the laboratory is not working hard enough or does not have the expertise to perform the work.
- Obtaining reference samples from a family member who was estranged from a victim can be difficult.
- DNA analysis may uncover situations in which biological relationships are not as reported. In such cases, the laboratory must have a policy. It may be advisable to consult with a bioethicist (see http://www.bioethics.net).
- If the mass fatality resulted from criminal or terrorist activity, family members may resist a mass burial that includes the remains of the perpetrator(s); they may not want any unidentified remains of their loved one commingled with the remains of the person or people who killed them.
- One of the most painful experiences for the family of a victim is learning that a misidentification requires exhumation. It also can be difficult for a family to receive additional remains after they have buried a loved one. A laboratory director should be prepared to encounter a wide range of wishes from the victims' families if such situations occur.