

## Putting the “Community” in Community Service

By Norman M. Goldfarb

Gulf Coast residents have borne – and continue bear – the brunt of Hurricane Katrina. But make no mistake about it – the Hurricane is a national disaster because it tests our concept as Americans of our national identity:

- **One Country.** Americans are Americans no matter where we live, without regard for race, creed or color.
- **Caring.** We donate of billions of dollars and billions of hours to charities without any legal obligation.
- **Individual Initiative.** In perhaps no other nation are individuals so empowered to take leadership roles without asking for anyone’s permission.
- **“Can Do” Attitude.** We pride ourselves on our ability to tackle and overcome tough challenges.

In this spirit, pharmaceutical and biotech companies reacted quickly to the Hurricane, committing over \$50 million of money and medical supplies, as well as thousands of hours of staff time within a few days. Individuals in the clinical research industry have made many, many personal contributions of time and money. However, few people in clinical research have yet perceived that Hurricane Katrina is also a huge opportunity to build the clinical research *community*.

Giving a hitch-hiker a ride out of the New Orleans floodwaters creates a qualitatively different relationship than sitting next to that same person at an industry conference. Hurricane Katrina gives the clinical research industry the opportunity to move beyond a community of conference attendees to become an extended “band of brothers.” Writing a check to a public relief fund is admirable, but it is also possible to leverage – at no extra cost – that same contribution into countless personal relationships that tie the community together.

The clinical research community is like any other business community, so can serve as a broader example. It includes pharmaceutical (and biotech and medical device) companies, academic and private clinical research sites, contract research organizations (CROs) and other suppliers, government funding and regulatory agencies, research subjects, and over 130 industry associations and 110 publications that serve the community directly or indirectly. Unlike most other industries, however, many participants play dual roles: Most research investigators are practicing physicians, so they have a dual supplier/customer relationship with pharmaceutical companies and study participants. Study participants are also patients, so they also have a dual relationship with both research investigators and pharmaceutical companies.

Hurricane Katrina damaged or destroyed dozens of research sites, dislocating hundreds of employees and thousands of study participants. Over two million U.S. residents will participate in industry-sponsored clinical research studies this year. Many participate entirely out of personal interest, but many others participate, at least in part, to help their community. Regardless of their reasons, their cooperation is essential for progress in medical science, and the survival of the clinical research industry. Study participants are as much members of the clinical research community as the researchers: Researchers give time; study participants also give time, usually plus blood and sometimes sweat and tears. Some of the Hurricane Katrina evacuees were participating in active clinical studies. Does the clinical research community have an obligation to help these members of our community? Clearly it does; that’s what it means to be members of a community.

There are several reasons why the clinical research community should act as a community, rather than as individuals: The community has unique resources for helping its members; acting as a community will create new and stronger relationships with future clinical research participants; and the effort will offset the negative, usually unfair, and sometimes bizarre treatment that clinical research receives from the media. Even without these reasons, the community itself will be far stronger as a result.

What unique resources does the clinical research community have to help its members? To start with, it knows who the likely victims are, and has numerous communication networks to help find them. Pharmaceutical companies and other organizations are already deploying assistance needed by victims in the community; they can leverage their efforts by working with other members of the community. Many members of the community are members because they are in "helping professions", i.e., they care about people.

Here is a concrete example of what the clinical research industry could do: Most large pharmaceutical companies have patient assistance programs that provide free or low-cost medicines to people who otherwise cannot afford them. If the pharmaceutical companies were to designate, say, 10% of these medicines for Hurricane Katrina victims within the community, it would give the rest of the community a feel-good reason to track down missing study participants, many of whom are in ill-health and just lost their health insurance. Research sites know where these people are, but are legally prohibited from disclosing their names to the pharmaceutical companies. By working together, the community can get medicines to members who need them, all the while building relationships within the community.

Even the most impoverished member of the community can help connect Hurricane victims and potential contributors into the network.

A new group, the Clinical Research Relief Organization (CRRO), is working to coordinate the clinical research community's relief efforts, especially with community-building approaches. Hurricane Katrina was especially horrific, but FEMA declares about 50 natural disasters a year. CRRO is likely to play an important role in the clinical research community for years to come.

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