

## MEDICAL SERVICES

## Savvy Patients Train Local Response Teams in Emergency PH Care

Last June, PH patient Judi Sepulveda sat down with eight paramedics at her local fire station in Anaheim, Calif., to conduct an informal training on Flolan. Using photocopies of information packets from her medication provider, Judi showed the group how to mix her medication and connect to her IV port. She also explained her special needs in an emergency situation. The paramedics found the training so helpful that they organized an in-service Flolan training for all of the 150 paramedics in the city of Anaheim. Today, Judi feels safer knowing that the EMTs in her area know her and her illness, understand how her medication works and know who to call for more information about adjusting her medication flow.

Judi is one of several PH patients who have decided to take their health into their own hands and share information about their illness with local EMTs. Several years ago, the Southern Colorado PH Support Group invited the paramedics from its local fire station to speak at a meeting on how to respond to emergency medical issues. What was originally intended as a lecture by the paramedics turned into a question and answer session with the patients, who explained their disease and the management needs of their life-saving medicines.

As in Anaheim, the paramedics in Colorado were eager to spread their newfound knowledge to the wider EMT community. Former Support Group Leader, Cheryl Massaro (see story, page 19), and other members of the group were brought in to educate a local team of EMTs. A registered nurse trained in Flolan management gave a medical perspective at this training and the session was taped and broadcast on short circuit television to multiple fire departments in the region. Since the training, the recording of Cheryl's session has been used to continue educating new paramedics.

Because of the complexity of administering some PH medications, specialty pharmacies recommend that patients get in touch with their local emergency response teams and alert them to their special needs prior to an emergency situation. According to Support Group Co-leader Pat Patterson, "EMTs are our life-line... We have a very specialized disease that's not common and any information that we can have available in advance to those treating us is going to make the outcome much brighter and easier to move through in any emergency."

### Tips for educating your local emergency response team:

- If you're not comfortable doing your own training, contact your specialty pharmacy to organize and conduct the training for you.
- Ask your EMT to put you on the BOLO, or "Be on the Lookout" list, which is a list of people who should be the first to receive attention, a check-in, electricity, or specific needs, in the event of a blackout, inclement weather, or disaster.
- Ask your EMT to tag your number in their system so that if you ever call 911, they'll be automatically alerted that you have special needs.
- Introduce yourself to the staff of your local fire department.
- Get on a list with your fire department, and provide them with answers to the following questions:
  - Are you on special medical treatments?
  - Do you use life sustaining oxygen?
  - Do you have liquid oxygen in your home?
- Think about what you would need from your local utility company in the event of a power outage or natural disaster (*e.g.* life sustaining equipment, refrigeration, oxygen, batteries and electricity).
- Take advantage of stickers you can put on your window that alert your local EMS to your condition and direct them to an "EMS File" detailing your specific needs, which you can keep on your refrigerator. They are sold by pharmacies, grocery stores and other local vendors.

