



## In emergency, children with special needs require individual plans

by Luann Zanzola  
Associate Editor

For a child with special health care needs, a trip to the emergency room can pose exceptional risks.

"Many of these kids are 1 in 100, 1,000 or 1 million, with medical problems that are unique to them," explained Robert Wiebe, M.D., FAAP, of Dallas.

"We had a child with muscular dystrophy who came into our emergency room in acute respiratory distress," recalled Dr. Wiebe, chair of the AAP Committee on Pediatric Emergency Medicine (COPEM).

"This is one of the rare occurrences when oxygen can be an enemy rather than a friend" due to the dynamics of the disease, he said. Medical personnel on duty were not familiar with muscular dystrophy, so "they put him on oxygen, he developed respiratory failure and died."

Another COPEM member, pediatric cardiologist Lee Pyles, M.D., FAAP, of Minneapolis, remembered when a West Virginia patient who'd had a Fontan procedure was taken to the ED with rapid heart beat.

Medical personnel there wanted to treat the boy with verapamil, as they would an adult, but the child's mother was aware the treatment "had the potential to make him very ill," Dr. Pyles said. "It took the mom a long time to convince the emergency physician to call a pediatric cardiologist. Eventually, he finally sent him to us for the correct treatment."

To avoid such frightening scenarios, pediatricians and parents should create an emergency plan — and make sure it's available 24 hours a day — for every child with chronic physical, developmental, behavioral or emotional conditions and medical needs beyond those of typically developing children.

Guidelines for creating these emergency plans have been developed by the Academy and the American College of Emergency Physicians (ACEP) and are available in a new AAP policy statement, "Emergency Preparedness for Children With Special Health



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"These children have very complicated histories, and, without their extensive medical records available, it's very hard to get a handle on what's going on," said Michael Gerardi, M.D., FACEP, FAAP, urging pediatricians to help develop, distribute and maintain emergency plans for their patients with special needs.

Care Needs" (*Pediatrics*, October 1999).

The statement "helps people to know the important points of how to start a program in their community," Dr. Pyles said. "There are so many rare pediatric diseases, and some of the emergency treatments are really very disease-specific. Then there are things like latex allergy that you have to know about right away."

Dr. Wiebe noted the guidelines also could help children who come to the ED with more common chronic health problems such as "sickle cell patients with their unique histories, asthmatics with their variety of medicines."

The statement has been in the works for two years, Dr. Wiebe said. "Two different parents (AAP and ACEP) are involved ... but the goals are the same: We're working together to try and become one voice for the children."

"We think this is probably one of the most — if not *the* most — useful initiatives ACEP and AAP have collaborated on," Dr. Wiebe said.

Michael Gerardi, M.D., FACEP, FAAP, of Randolph, N.J., is ACEP's consultant to the Academy on the policy statement. He will discuss the emergency initiative and information form during a plenary session at 9:20 a.m. Oct. 10 at the AAP Annual Meeting, and again later that week in Las Vegas, as chair of ACEP's emergency medicine committee at the ACEP annual meeting.

"These children have very complicated histories, and without their extensive medical records available, it's very hard (for emergency room personnel) to get a handle on what's going on," said Dr. Gerardi. For him, the issue hits close to home.

"I have a son with congenital heart disease," he said, admitting he's wondered for years whether, if he weren't available, the scars on his son's body would be an adequate signal to physicians of the potential for problems during emergency treatment.

"We've all taken care of children with scars on their chest and abdomen, or with a bag full of medicine," Dr. Gerardi said, "and (in an emergency) you just can't quite get enough out of the parents."

The policy statement recommends that emergency care plans include:

- use of a standardized form;
- a method of identifying at-risk children;
- completion of a medical information data set (like the information form) by the child's physicians;
- education of families, caregivers and health care professionals on use of the emergency plan;
- regular updates of the information;
- 24-hour access to the information by authorized emergency health care professionals; and
- maintenance of patient confidentiality.

Of these, identifying the at-risk children poses a major hurdle. According to Dr. Wiebe, there are a variety of ways to do this, such as requiring the forms to be on file with parents, schools and child care providers.

"Some EMS agencies are capable of having this in their 911 system," he added, and some hospitals have databases that can accommodate the information.

Another way, popular worldwide for medical emergencies, is by having the child constantly wear a MedicAlert bracelet or necklace. The jewelry, inscribed with basic but critical medical information, is sold through the nonprofit MedicAlert Foundation, based in California.

Directors of MedicAlert have indicated a willingness for the network to serve as a universal repository for information on children with special needs. The organization also is working with the Academy and ACEP to test the emergency form in a pilot study conducted with the New Jersey Department of Health and Human Services, through a grant from the federal Emergency Medical Services for Children agency. The study will run through June 30, 2000.

With such vital medical data so widely accessible, maintaining patient confidentiality is a concern — but a lesser one. "We think

it's an overstated issue, in all honesty," said Dr. Gerardi.

Dr. Pyles added that, during focus group sessions conducted with families in a West Virginia pilot study, "What we heard from families is, if they have a child with a really serious problem, [confidentiality] is really a very minor issue to them. Their focus is on getting care for their children."

Dr. Wiebe agreed. "That's a minor issue when it comes to protecting the lives of children. ... (confidentiality) can be managed in this day and age. I'm more concerned with the continual update."

He believes the forms should be updated as often as necessary by the primary care provider, medical home or gatekeeper. When changes occur, "It's important that the specialists and subspecialists communicate these things to the primary care provider" so the information is accurate.

Dr. Gerardi added, "We prefer to talk to the patient's pediatrician or specialist, but that is not always possible. This doesn't supplant the subspecialist consultation ... this is in lieu of being able to get in touch with them. We don't care who fills out the form, as long as it's accurate."

Dr. Wiebe also fears some health care providers might resent having yet another form to fill out, but Dr. Gerardi points out the process needn't be time-consuming. "Just because there's two pages, they don't have to fill it out entirely either ... Just a number where they can be reached, allergies ... I'm worried about the essential, critical data.

"If I had enough time," he added, "I'd sit and fill out *all* these forms, that's how strong I feel about it."

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*For more information, contact Sue Tellez in the AAP Division of Hospital and Surgical Services at (800) 433-9016, ext. 7395.*

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*A two-page, reproducible standardized emergency information form, bound into this month's AAP News, can be downloaded from the AAP ([www.aap.org](http://www.aap.org)) and ACEP ([www.acep.org](http://www.acep.org)) Web sites, and is available in pads of 100 from the AAP Department of Marketing and Publications at (888) 227-1770.*