AMERICAN ACADEMY OF PEDIATRICS

Committee on Pediatric Emergency Medicine

Emergency Preparedness for Children With Special Health Care Needs

ABSTRACT. Children with special health care needs are those who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount not usually required by typically developing children. Formulation of an emergency care plan has been advocated by the Emergency Medical Services for Children (EMSC) program through its Children With Special Heath Care Needs Task Force. Essential components of a program of providing care plans include use of a standardized form, a method of identifying at-risk children, completion of a data set by the child's physicians and other health care professionals, education of families, other caregivers, and health care professionals in 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. *Pediatrics* 1999;104(4). URL: http://www.pediatrics.org/cgi/content/full/104/4/e53; *children, special health care needs, emergency preparedness.*

ABBREVIATIONS. US DHHS-MCHB-NHTSA EMSC, US Department of Health and Human Services, Maternal and Child Health Bureau, National Highway Traffic Safety Administration, Emergency Medical Services for Children; EMS, emergency medical services; AAP, American Academy of Pediatrics.

Emergency care of children with special health care needs is frequently complicated by a lack of a concise summary of their medical condition, precautions needed, and special management plans. This policy statement introduces a standardized information form that can be used to prepare the caregivers and health care system for emergencies of children with special health care needs. Emergency data sets, summaries, or "passports" have been used in several of the US Department of Health and Human Services, Maternal and Child Health Bureau, National Highway Traffic Safety Administration, Emergency Medical Services for Children (US DHHS-MCHB-NHTSA EMSC) demonstration grant projects. Use of such emergency data has been advocated by the EMSC program through its Children With Special Health Care Needs Task Force. This statement describes essential components of an emergency information program. Figures 1 and 2 show a blank form and a sample form. Implementation of this program by a pediatrician or other health care professional or as part of a comprehensive EMSC program in a state will improve the ability to care for children with special needs.

Children with special health care needs are those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount not usually required by children.[1] Children with special health care needs frequently require emergency care for acute life-threatening complications that are unique to their chronic conditions. Emergency hospital and prehospital care is believed to be negatively affected by a frequent lack of accurate timely information about the children's special needs and particular histories.

To address this identified need for the group of children with special needs, creation of a passport plan or emergency medical information set has been advocated by the US DHHS-MCHB-NHTSA EMSC program through its Children With Special Health Care Needs Task Force Report of January 1997. The report notes:

> "If the child is at risk for future medical emergencies, the child and family should participate in developing a written emergency care plan. Copies of this plan should be kept in easily accessible places at the child's home and any other location where the child regularly spends time. The plan should include provisions for any special training that will be needed by emergency medical personnel, family members, or other persons who may be called on to provide emergency care for the child."[2]

To date, the efficacy of this method in improving care for children with special needs has not been studied. However, several US DHHS-MCHB-NHTSA EMSC projects have used an emergency information set in populations with special needs. Projects in New Mexico, Wisconsin, Ohio, and the Ohio–Kentucky–West Virginia region have used wallet cards or 1-page summaries that are given to parents.[3] The wallet cards have separate pages for demographics, diagnoses, conditions, and medications and can be updated by exchanging single cards. Currently in West Virginia, a single page (front and back) summary is being tested throughout the West Virginia MCHB Children With Special Health Care Needs Division.[4] Adjuncts to the program include window stickers identifying the homes of children with special needs and linkage to an emergency telephone number such as 911, which will alert emergency medical service (EMS) professionals to look in the refrigerator for a vial containing the summary. Sherman and Capen[5] recently described a program to streamline and standardize access to care for asthmatic children with a history of life-threatening events. Termed the *Red Alert Program*, the parents,

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians® | American Academy of Pediatrics

Date form completed By Whom	Revised	Initials
	Revised	Initials

Name:	Birth date: Nickname:
Home Address:	Home/Work Phone:
Parent/Guardian:	Emergency Contact Names & Relationship:
Signature/Consent*:	
Primary Language:	Phone Number(s):

Physicians:	
Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:

1 .	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Fig 1. Emergency information form for children with special needs.

health care professionals, EMS providers, schools, and emergency physicians were educated about the need for early access to aggressive acute treatment of the child's asthma, and the parents were given written documentation of the history of severe asthma.

The emergency information set or passport should

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

1.
2.
3.
4.
5.
6.

Significant baseline ancillary findings (lab, x-ray, ECG):

Prostheses/Appliances/Advanced Technology Devices:

Last name:

Management Data:

Allergies: Medications/Foods to be avoided **and why:**

1.
2.
3.

Procedures to be avoided **and why:**

1.
2.
3.

Immunizations

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: **Print Name:**

Fig 1. Continued.

result in improvement in the emergency care of children with special health care needs. The emergency information set should be considered a part of the overall plan of service advocated by the American Academy of Pediatrics' (AAP) Committee on Children With Disabilities.[6] In addition, completion of

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians®

American Academy of Pediatrics

Date form completed 1/1/97	By Whom J. Heart, MD	Revised 5/15/98	Initials JH
		Revised	Initials

Name: Blue, Little B.	Birth date: 7/4/96 Nickname: LB
Home Address: 1313 Mockingbird Lane, Anytown, USA, 11111	Home/Work Phone: 900-555-1212 (home) 777-8899 (work)
Parent/Guardian: Sandra Blue, mother	Emergency Contact Names & Relationship: Beatrice Blue, grandmother
Signature/Consent*: Sandra Blue	
Primary Language: English	Phone Number(s): 900-444-5566

Physicians:

Primary care physician: Marcus Welby, MD	Emergency Phone: 1-800-KIDS-RUS
	Fax: 000-000-0000
Current Specialty physician: Specialty: P. Card. Jime Heart, MD	Emergency Phone: 000-000-0000
	Fax: 000-000-0000
Current Specialty physician: Specialty: P. Neuro. Joe Neuro, MD	Emergency Phone: 000-000-0000
	Fax: 000-000-0000
Anticipated Primary ED: Smallville Hospital	Pharmacy:
Anticipated Tertiary Care Center: Childrens All Star Regional Med Center	

Diagnoses/Past Procedures/Physical Exam:

1. tetralogy of Fallot with pulmonary atresia; RV to PA conduit 2/97 VSD left, ductus and collaterals ligated	Baseline physical findings: gr III harsh murmur, few crackles at base of left lung, liver down 5 cm.
2. Asplenia syndrome	
3. thrombosed bilat femoral, iliac veins and inferior vena cava	Baseline vital signs: P 90 BP 100/50 R 24, O_2 Sat 85% Weight: 12 kg Date: 5/15/98
4. Seizure disorder: generalized tonic-clonic	
Synopsis: Asymptomatic, mildly cyanotic nb. Asplenia syndrome noted. Surgery of RV to PA conduit at 8 mos. of age. Post-op seizures-mild R CVA, hemiparesis resolved.	Baseline neurological status: Awake, age appropriate, interactive. Mild increased tone L>R. EEG 5/97: Mild assymetry with right-sided slowing

*Consent for release of this form to health care providers

Fig 2. Sample emergency information form for children with special needs.

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

1. Digoxin 50 mcg=1cc BID
2. Lasix 10 mg BID
3. Amoxil 200 mg BID
4. Phenobarb 40 mg BID
5.
6.

Significant baseline ancillary findings (lab, x-ray, ECG):

moderate cardiomegaly on cxr

chronic LLL atelectasis on cxr

RVH on EKG

Prostheses/Appliances/Advanced Technology Devices: homograft conduit RV to MPA — no extra precautions. Sternal wires and clips on vessels — no MRI until 6 mos post-op

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1. Betadine	rash
2.	
3.	

Procedures to be avoided	and why:
1. femoral venous puncture	no fem veins
2. instillation of air into venous catheters	R to L intracardiac shunt
3.	

Immunizations

Dates	9/4/96	11/4/96	1/4/97	1/10/98	
DPT	X	X	X	X	
OPV	X	X	X	X	
MMR				X	
HIB	X	X	X		

Dates	9/4/96	11/4/96	1/4/97	1/10/98	
Hep B		X			
Varicella					
TB status					
Other				Pneumovax	

Antibiotic prophylaxis: Indication: Asplenia
SBE Prophylaxis

Medication and dose: Amoxil 200 mg BID
Amoxil 50 mg/kg one hour prior to procedure

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations
Worsened CHF	cxr	increase lasix
Status Epilepticus	check electrolytes-Na check phenobarbitol level	midazolam, correct lytes
Fever	sepsis w/u	broad spectrum atbx for asplenic individual

Comments on child, family, or other specific medical issues: Mother is an excellent caregiver a nd knows when LB is blue.

Physician/Provider Signature: Jime Heart MD **Print Name:** Jime Heart, MD

Fig 2. Continued.

the summary will fulfill the need for a medical history for any child wanting to participate in child care, school, day camp, or resident camp.[7] Implementation of this program through a pediatrician or other health care professional, in a child care facility, through a school system,[8] or as part of a comprehensive EMSC program will improve the ability to care for these children.

RECOMMENDATIONS

The AAP offers the following recommendations[9]:

1. A brief, comprehensive summary of information important for hospital or prehospital emergency management of a child with special health care needs should be formulated by the child's caregivers, health care professionals, and all subspecialty providers.
2. The summary, or emergency medical data set, should be updated regularly and maintained in an accessible and usable format.
3. Parents, other caregivers, and health care professionals should be educated to optimize use of the summary. Parents and other caregivers should be encouraged to take the summary with them for all health care encounters.
4. Mechanisms to quickly identify children with special health care needs in an emergency should be established and should be available to local EMS and hospital personnel.
5. A universally accepted, standardized form should be used for summaries. Figures 1 and 2 show a suggested form entitled "Emergency Information Form for Children With Special Health Care Needs." Essential data elements include the patient's name, birth date, date of last summary update, weight, guardian's name, emergency contacts, pediatricians and other health care professionals, primary emergency department, major chronic illnesses and disabilities, baseline physical and mental status, baseline vital signs and laboratory studies, immunization history, medications, medication allergies, food allergies, and advanced directives.* The AAP and its chapters should encourage local adoption of the American College of Emergency Physicians/American Academy of Pediatrics form.
6. Rapid 24-hour access to the summary should be ensured. Copies should be accessible at home, school, during transportation, and in the emergency department in addition to a copy in the records of treating physicians. Linkage to an emergency telephone number such as a 911 dispatch or some other method of assuring rapid access is desirable. Especially important is identification of the most appropriate EMS squad to be called in areas without a 911 dispatch. Schools and child care facilities should be encouraged to include the emergency summary as part of a child's individual health plan.
7. Confidentiality of the form should be carefully maintained. Parental permission to establish the emergency information form and distribute it to appropriate agencies should be obtained and kept on file with the originator of the form or at a central repository.

COMMITTEE ON PEDIATRIC EMERGENCY MEDICINE, 1998–1999
Robert A. Wiebe, MD, Chairperson
Barbara A. Barlow, MD
Ronald A. Furnival, MD
Barry W. Heath, MD
Steven E. Krug, MD
Karin A. McCloskey, MD
Lee A. Pyles, MD
Deborah Mulligan-Smith, MD
Timothy S. Yeh, MD

LIAISON REPRESENTATIVES
Richard M. Cantor, MD
American College of Emergency Physicians
Dennis W. Vane, MD
American College of Surgeons
Jean Athey, PhD
Maternal and Child Health Bureau
David Markenson, MD
National Association of EMS Physicians

AAP SECTION LIAISONS
Joseph P. Cravero, MD
Section on Anesthesiology
M. Douglas Baker, MD
Section on Emergency Medicine
Michele Moss, MD
Section on Critical Care
Dennis W. Vane, MD
Section on Surgery

CONSULTANT
Michael J. Gerardi, MD

* Most states have a standard advanced directive form, which is required for EMS to honor the advanced directive to withhold emergency lifesaving measures; however, the emergency data set or summary can identify a need to look for the standard form.

REFERENCES

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998;102:137–140
2. Emergency Medical Services for Children, National Task Force on Children With Special Health Care Needs. EMS for children: recommendations for coordinating care for children with special health care needs. *Ann Emerg Med.* 1997;30:274–280
3. National Center for Education in Maternal and Child Health. *Emergency Medical Services for Children. Abstracts of Active Projects FY 1994.* Arlington, VA: National Center for Education in Maternal and Child Health; 1994
4. *Emergency Medical Services for Children: Abstracts of Active Projects FY 1997.* Torrance, CA: National Emergency Medical Services for Children Resource Alliance; 1997
5. Sherman JM, Capen CL. The Red Alert Program for life-threatening asthma. *Pediatrics.* 1997;100:187–191
6. American Academy of Pediatrics, Committee on Children With Disabilities. Pediatric services for infants and children with special health care needs. *Pediatrics.* 1993;92:163–165
7. American Academy of Pediatrics, Committee on School Health. Medical guidelines for day camps and residential camps. *Pediatrics.* 1991;87:117–119
8. American Academy of Pediatrics, Committee on School Health. Guidelines for urgent care in school. *Pediatrics.* 1990;86:999–1000
9. Sacchetti A, Gerardi M, Barkin R, et al. Emergency data set for children with special needs. *Ann Emerg Med.* 1996;28:324–327