



Care Notebook



Please accept this copy of the FVND Care Notebook.

You may copy the pages for your use.

Please direct any comments, suggestions or questions to:

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Family Voices of North Dakota
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FVND Care Notebook: A Quick Guide



What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs or disabilities. Use a Care Notebook to **keep track of important information about your child's health care.** This Care Notebook has been designed for families living in North Dakota.



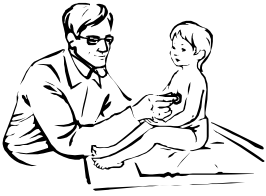
How can a Care Notebook help me?

In caring for your child with special health needs and/or disabilities, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share **key information** with others who are part of your child's care team.



Use your Care Notebook to:

- Track changes in your child's medicines or treatments
- List telephone numbers for health care providers and community organizations
- Prepare for appointments
- File information about your child's health history
- Share new information with your child's primary doctor, public health or school nurse, daycare staff, and others caring for your child



What are some helpful hints for using my child's

Care Notebook?

- ❑ Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.
- ❑ *Add new information to the Care Notebook whenever your child's treatment changes.*
- ❑ Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find.

Setting up Your Care Notebook



Follow these steps to set up your **child's notebook**:

Step 1: Gather information you already have.

- Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

Step 2: Look through the pages of the Care Notebook.

- Which of these pages could help you keep track of information about your child's health or care?
- Choose the pages you like. Print copies of any that you think you will use. The Care Notebook pages are available from the Internet at www.geocities.com/ndfv/ Go to Resources Page and choose the "Care Notebook."

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- What information do you look up often?
- What information do people caring for your child need?
- Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

- ❑ Everyone has a different way of organizing information. The only important thing is to make it easy for you to find again. Here are some suggestions for supplies used to create a Care Notebook:
- ❑ 3-ring notebook or large accordion envelope. Hold papers securely.
- ❑ Tabbed dividers. Create your own information sections.
- ❑ Pocket dividers. Store reports.
- ❑ Plastic pages. Store business cards and photographs.



FVND Care Notebook

List of Pages

Pages to Keep Track of Appointments and Care

- ☀ Appointment Log
- ☀ Diet Tracking Form
- ☀ Equipment
- ☀ Supplies
- ☀ Growth Tracking Form
 - ☀ Growth Charts
- ☀ Hospital Stay Tracking Form
- ☀ Information Needed by Emergency Care Providers
- ☀ Lab Work/Tests/Procedures
- ☀ Medical Bill Tracking Form
- ☀ Medical Surgical Highlights
- ☀ Medications
- ☀ Notes

Pages to Create a Care Summary: Abilities and Special Care Needs

- ☀ Activities of Daily Living
- ☀ Care Schedule
- ☀ Child's Page
- ☀ Communication
- ☀ Coping/Stress Tolerance
- ☀ Mobility
- ☀ Nutrition
- ☀ Respiratory
- ☀ Rest/Sleep
- ☀ Social/Play
- ☀ Transitions

Pages to Create a Care Team Resource List

Community Health Care/Service Providers:

- ☀ Medical / Dental
- ☀ Public Health
- ☀ Home Care
- ☀ Therapists
- ☀ Early Intervention Services
- ☀ School
- ☀ Child Care
- ☀ Respite Care
- ☀ Pharmacy
- ☀ Special Transportation
- ☀ Recreation Opportunities
- ☀ Family Information
- ☀ Family Support Resources
- ☀ Funding Sources

Note: You may use all or just a part of these pages. Not all of the pages may apply to your family situation. For example, your child may be over age 3, and therefore not involved in Early Intervention.

Organize your pages any way that works for you. (See "[Setting up Your Care Notebook](#).")

Use dividers or tabs to help you organize your notebook. Sheet protectors, plastic pages and folders will also be helpful in organizing material.

Diet Tracking Form

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

Equipment

☼ Medical Equipment Supplier (DME Supplier): _____

Contact Person: _____

Phone: _____ Fax: _____ E-Mail: _____

Contact Person: _____

Phone: _____ Fax: _____ E-Mail: _____

Address: _____

Notes (delivery schedule, order schedule, etc.): _____

☼ Name of Equipment: _____

Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____

Contact Person: _____ Phone: _____

☼ Name of Equipment: _____

Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____

Contact Person: _____ Phone: _____

☼ Name of Equipment: _____

Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____

Contact Person: _____ Phone: _____

Emergency Preparedness for Children with Special Health Care Needs *Instructions for Parents*

Dear Parent:

Children with special health care needs have very unique medical histories and require very special medical treatment. If an emergency physician does not have access to this important information, these children are in danger of delayed treatment, unnecessary tests, and even serious errors. It is extremely important, then, that parents and physicians work together to give emergency physicians access to the special information they need to properly care for children with very special health care needs.

To address this problem, the American Academy of Pediatrics and the American College of Emergency Physicians have developed the Emergency Information Form. This simple form is used to record health information for children with special health care needs and should be kept in multiple locations for easy access by physicians and emergency medical personnel.

To complete this important form, follow these easy instructions:

1. **GET THE FORM:** Get the Emergency Information Form from the child's primary care physician, specialist, or the local emergency room.
2. **FILL IT OUT:** Begin filling out the form to the best of your ability. Take the form to the child's primary care physician or specialist and ask them to finish filling out the form.
3. **KEEP IT:** Keep 1 copy of the form in each of the following places:
 - a. **DOCTORS:** On file with each of the child's physicians, including specialists.
 - b. **ER:** On file with the local emergency rooms where the child is most likely to be treated in the case of an emergency.
 - c. **HOME:** At the child's home in a place where it can be easily found, such as the refrigerator.
 - d. **VEHICLES:** In each parent's vehicle (i.e., glove compartment).
 - e. **WORK:** At each parent's workplace.
 - f. **PURSE/WALLET:** In each parent's purse or wallet.
 - g. **SCHOOL:** On file with the child's school, such as in the school nurse's office.
 - h. **CHILD'S BELONGINGS:** With the child's belongings when traveling.
 - i. **EMERGENCY CONTACT PERSON:** At the home of the emergency contact person listed on the form.
4. **REGISTER:** Consider registering the child, if he or she is not already registered, with Medic Alert®. Send Medic Alert® a copy of the form so that they can keep it stored in their central database, which is easily accessible by emergency medical personnel.
5. **UPDATE:** It is extremely important that you update the form every 2-3 years, and after any of the following events:
 - a. Important changes in the child's condition.
 - b. The performance of any major procedure.
 - c. Important changes in the treatment plan.
 - d. Changes in physicians.

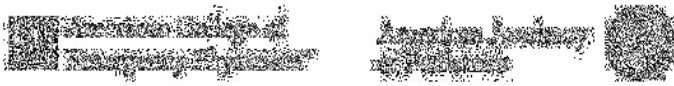
Now, if your child ever has an emergency, the emergency medical personnel will have easy access to your child's very unique medical history, allowing them to provide your child with the best medical care available.

Thank you for your cooperation!

Very truly yours,
American Academy of Pediatrics
American College of Emergency Physicians
Emergency Medical Services for Children

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American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL, 60007, 847-434-4000

Emergency Information Form for Children With Special Needs



Date form completed	Revised	Initials
By Whom	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

Diagnoses/Past Procedures/Physical Exam continued:	
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:	
<i>Allergies: Medications/Foods to be avoided</i>	and why:
1. _____	_____
2. _____	_____
3. _____	_____
<i>Procedures to be avoided</i>	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations (mm/yy)											
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: _____

Medical Bill Communication Log

Information About the Bill				Information About Who You Talk To					NOTES
Account #	Provider	Date of Service	What bill is for:	Date of Contact	Time	Name	Title (like Account Representative)	Credentials (RN, Dr., none)	

Medical / Surgical Highlights

DATE	PROCEDURE	RESULT	COMMENTS

Medications

Allergies: _____

Pharmacy: _____

Address: _____ Phone: _____

Fax: _____ E-Mail: _____

DATE STARTED	DATE STOPPED	MEDICATION	WHAT IT IS FOR	DOSE/ROUTE	TIME GIVEN	PRESCRIBED BY	SIDE EFFECTS

Care Schedule

TIME	CARE
Morning	

Care Schedule

TIME	CARE
Evening	
Night	

Child's Page



My name is: _____

My nickname is: _____

My pet is a: _____ My pet's name is: _____

My "favorites"

Toys: _____

Animal: _____

Games: _____

Hobbies: _____

Songs: _____

T.V. Shows: _____

Other: _____

My favorite foods are: _____

My least favorite foods are: _____

My friends' names are: _____

When I am happy I: _____

When I am sad I: _____

When I feel pain I: _____

Things I need help with (like washing, dressing or brushing teeth): _____

Things I can do for myself (but thanks for asking!): _____

If you need to know something else, ask me or ask: _____

who can be reached by calling: () _____

Communication

Use this page to talk about your child’s ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date: _____

Nutrition

Use this page to talk about your child’s nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date: _____

Respiratory

Use this page to talk about your child’s respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date: _____

Rest / Sleep

Use this page to talk about your child's ability to get to sleep and to sleep through the night.
Describe your child's bedtime routine and any security or comfort objects your child uses.

Date: _____

Social / Play

Use this page to talk about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Date: _____

Transitions - Looking Ahead

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date: _____

Medical / Dental

Community Health Care Providers

☼ Primary / Community Care Provider: _____
Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Primary Children's Medical Center
Medical Record Number: _____
Address: _____
Phone: _____ Fax: _____

☼ Community or Specialty Hospital: _____
Medical Record Number: _____
Address: _____
Phone: _____ Fax: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Dental Provider: _____
Date of First Visit: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Orthodontist: _____
Date of First Visit: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

There is space to list more Specialty Care Providers on the next page.

Providers (Continued)

Many specialty physicians may treat your child. You may keep track of some them here:

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

☼ Community Specialty Care Provider: _____
Specialty: _____ Date of First Visit: _____
Office Nurse/Medical Assistant: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

Home Care Providers

☼ Home Care Agency: _____

Start Date: _____

Case Manager: _____

Other Contacts (scheduler, billing, etc.): _____

Primary Care Nurse: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Home Care Agency: _____

Start Date: _____

Case Manager: _____

Other Contacts (scheduler, billing, etc.): _____

Primary Care Nurse: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Home Care Agency: _____

Start Date: _____

Case Manager: _____

Other Contacts (scheduler, billing, etc.): _____

Primary Care Nurse: _____

Phone: _____ Fax: _____ E-Mail: _____

Therapists

☼ Occupational Therapist (OT): _____

Start Date: _____

Agency / Hospital / Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Physical Therapist (PT): _____

Start Date: _____

Agency / Hospital / Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Speech-Language Pathologist: _____

Start Date: _____

Agency / Hospital / Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Early Intervention

☼ The Early Intervention Program Early intervention means early assistance. Here in North Dakota, a special kind of partnership between parents and professionals gives every child the best possible start in life. The Department of Human Services' Infant Development/Early Intervention programs are designed to help your child and your family gets the supports you want and need. This program is designed to identify children at risk in the earliest stages, when the right help can make all the difference. This program is to support eligible children and families in enhancing a child's potential growth and development from birth to age three.

☼ My Early Intervention Program agency: _____
 Date contacted: _____ Date started in program: _____
 Service Coordinator: _____
 Service Providers (therapist, nurse, etc.): _____
 Address: _____

 Phone: _____ Fax: _____ E-Mail: _____
 Schedule: _____

If you live in this Region:	Contact this Agency:	At this Telephone Number:
Williston	Northwest Human Service Center	701-774-4600
Minot	Minot State University	701-858-3054
Devils Lake	Lake Region Kids	701-662-6324
Grand Forks	Northeast Human Service Center	701-795-3000
Fargo	Southeast Human Service Center	701-298-4500
Jamestown	South Central Human Service Center	701-253-6300
Bismarck	Bismarck Early Childhood Education Program	701-221-3490
Dickinson	K.I.D.S.	701-483-4394

School Contacts

☼ School District: _____
Address: _____
Phone: _____ Fax: _____ Web Site: _____

Special Education Coordinator: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

504 Accommodation Plan Coordinator (if different from above): _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

District Nurse assigned to your child's school: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____

.....
☼ School / Preschool: _____
Address: _____
Phone: _____ Fax: _____ Web Site: _____

Principal / Administrator: _____
Phone: _____ Fax: _____ E-Mail: _____

Classroom Teacher: _____
Phone: _____ Fax: _____ E-Mail: _____

Resource Instructor: _____
Phone: _____ Fax: _____ E-Mail: _____

Aide / Assistant / Intervener: _____
Phone: _____ Fax: _____ E-Mail: _____

(Some parents store IEP and 504 plan information in sheet protectors following this section.)

Special Education Director / Teacher(s): _____
Phone: _____ Fax: _____ E-Mail: _____

Therapist(s): _____
Phone: _____ Fax: _____ E-Mail: _____

Other Contacts: _____

Child Care

☼ Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important Information: _____

☼ Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important Information: _____

☼ Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important Information: _____

Respite Care

☼ Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

If applicable:

Fiscal Agent: _____ Contact: _____

Phone: _____ Fax: _____ E-Mail: _____

Pharmacy

Medical professionals suggest that, if possible, you use one pharmacy for all your prescription medicine needs. In this way, your pharmacist may keep track of all medications being used and any possible problems with interactions between medications. Sometimes, however, you may need to have prescriptions filled at your neighborhood pharmacy and other times you may need to have them filled at the hospital pharmacy. Use this space to keep track of all your pharmacy providers.

☼ Pharmacy: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Pharmacy: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Pharmacy: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important information for the pharmacist (Such as allergies to medication):

Special Transportation

☼ Transportation (to and from medical / therapy appointments):

Contact person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important information (such as bus route, rules regarding pick-up, etc.):

☼ Transportation (to and from medical / therapy appointments):

Contact person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Important information (such as bus route, rules regarding pick-up, etc.):

Recreation

A number of organizations have programs designed to give children and adults with special needs Recreation opportunities. These include local park and recreation programs. Check with your providers to find out more about recreation opportunities close to your home. Some parents include brochures and activity calendars in this section of their Family Voices of North Dakota Care Notebook.

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

Notes: _____

Family Information

☼ Child's Name: _____ Nickname: _____
Date of Birth: _____ Social Security Number: _____
Diagnosis: _____
Blood Type: _____

Legal Guardian: _____
Address: _____ Phone: _____

Family Members

☼ Mother's Name: _____
Social Security Number: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____

☼ Father's Name: _____
Social Security Number: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____

☼ Sibling's Name: _____ Age: _____ Name: _____ Age: _____
☼ Sibling's Name: _____ Age: _____ Name: _____ Age: _____

☼ Other household members: _____

☼ Important Family Information: _____

☼ Language spoken at home: _____
Other language(s): _____
Interpreter Needed? Yes: _____ No: _____
Preferred interpreter? Name: _____ Phone: _____

Emergency Contact

☼ Name: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____

Family Support Resources

☼ Support Group / Organization: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Support Group / Organization: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Religious Organization: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Counseling Services: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Department of Human Services: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Other: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

☼ Other: _____
Contact Person: _____
Address/Directions: _____

Phone: _____ Fax: _____ E-Mail: _____

Insurance, Etc.

☼ Primary Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____

☼ Secondary Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____

☼ Medicaid (HMO Name if applicable – this is the company name that appears above your child’s name and ID Number on the Medicaid Identification Card): _____
ID Number: _____
Eligibility Worker: _____
Office/Location of Eligibility Worker: _____
Phone: _____ Fax: _____

☼ Supplemental Security Income (SSI): _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____

☼ Other: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____

