

# Personal Health Records



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# Getting Jason's Health Records

Shelly's son Jason has many health issues. She depends on his primary care doctor, Dr. Roberts. He gives routine care. He also helps arrange Jason's health care and other services. Shelly just found out that Dr. Roberts is retiring soon. She needs to find a new primary care doctor for Jason. With the help of Dr. Roberts and Jason's case manager, Shelly was able to find a new doctor. She decides to take Jason to Dr. Jones. The new doctor's office wants copies of all of Jason's health records before the first appointment.

Shelly is confused about how to get Jason's records for Dr. Jones. Jason goes to many different doctors so he has many different records. Shelly has some of his health records, but not all of them. The records she has are all in a box and are not organized.

- What can Shelly do to get Jason's health records?
- How can she keep an organized copy of Jason's health records?



# What's It All About

Health records have information about health problems, growth, test results, medicines, and other treatments. Health care providers write notes and add new information over time. Health records are also called “medical records.” They may be paper, electronic, or pictures such as an X-Ray or ultrasound.

Your child has health records in many places. There is a record wherever care has been given such as at a doctor's or dentist's office, hospital, clinic, or school. Records may also be at a health insurance company, pharmacy, or home health company.

Having health information spread across many places can cause problems. Providers don't all have the exact same information. Each provider has some of your child's records but usually no one has all of it. It may be hard to get records at night, during emergencies, and when traveling. Without complete information, care may be delayed, unnecessary, or unsafe.

You can help by keeping a personal health record (PHR). A PHR has copies of medical and school health records in one place. You can also add information that others don't have such as family history, notes you keep, or medical bills

A PHR makes it easier to keep track of health information and share it with doctors, teachers, and others. Having a PHR helps make sure everyone has the information needed to care for your child.

## Steps to Learn About Personal Health Records

1. Make a Personal Health Record (PHR).
  - Gather important medical and school health records.
  - Gather other information you want to include.
2. Keep PHR organized and up to day.
  - Organize PHR so that you can find what is needed easily.
  - Make a plan for how to keep it up to date.
3. Give records to providers, schools, and others when needed.
  - Get a folder for keeping records that providers may need.
  - Keep up to date health information in the record.
  - Take it to clinic visits, meetings, the emergency room, etc.

# Take Action

## Keep A Personal Health Record (PHR)

A PHR is different than a medical record.

- Health care providers are responsible for medical records.
  - They keep them safe and private.
  - They usually can't share records without your permission.
  - They decide what information to put in medical records.
- You are responsible for your child's PHR
  - You keep the PHR at home or with you.
  - You decide who can see the information and what to share.
  - You decide what information to put in PHR.
- Think about what type of information to keep in your child's PHR. Use the list below as a guide.



### Examples of Information to Keep in the PHR

#### Health Information

Doctor, therapy, and home nursing records  
Your notes  
Growth chart  
Allergy list  
Medicine list  
Family history  
Treatment schedule  
Equipment and supply information

#### School Information

Individual Health Plan (IHP)  
Individual Education Plan (IEP)  
Evaluations and report cards  
Your notes from meetings

#### Insurance Information

Copy of your health insurance policy  
Application for Katie Beckett or public health insurance  
SSI information  
Life insurance policy

#### Financial

Medical expense logs  
Medical bills  
Trust fund papers

#### Legal

Living Will  
Guardianship papers  
Power of health care attorney papers

# Take Action

## Getting health and school records

Figure out what records you have and what you need to get.

- Two checklists in this section may help you decide.

The “Health Record Checklist”

The “School Record Checklist”

- You probably don’t need every record
- Ask if you’re not sure what records to keep in the PHR.

Find out where to get the records you need.

- The provider who gave care usually has the records.
- Records from a hospital stay or hospital clinic are in the Medical Records Department
- Get lab, x-ray, and other test results from the doctor who ordered them.
- School records are also called education records.
- Ask if you are not sure where to get records.

Get copies of health and school records

- You have the right to see and get copies if:
  - Your child is less than 18 yrs old.
  - You are the legal guardian (of any age of person).
- You must ask for copies of health records in writing.
  - Most providers have a form you can use.
  - Keep a copy of the form and make sure it has a date.
- You may have to pay for copies.
  - The price is for time spent copying records, paper, and mailing.
  - Ask the cost before copies are made.

## Know Your Rights About Health Records

### HIPAA (Health Insurance and Portability

**Accountability Act)** protects health information and gives you the right to:

- See and get copies of health records.
- Have information be kept safe and private.
- Ask that the record be changed if you think it’s wrong.
- Decide who can see information. Sometimes your permission isn’t needed, such as during emergencies.
- Get a written notice about the law and your rights
- Know when, why, and with whom records were shared.
- File a complaint if health information wasn’t protected.

## Know Your Rights About School Records

### FERPA (Family Educational Rights and Privacy Act)

keeps school records private and gives you the right to:

- See and get copies of school records.
- Ask that record be changed if you think it’s wrong.
- Ask someone to explain school records to you.
- Decide if outside agencies or people who are not school employees can see the records,
- Know when, why and with whom records were shared.
- Make a complaint to the school or government if you think records weren’t kept private.

**See Resources page to learn more about these two laws.**

# Take Action

## Keep Personal Health Record (PHR) organized

Take time to organize records.

- You can do it all at once or a little at a time.
- There isn't one right way to organize PHR. Organize records so that:
  - Everything is in one, easy to reach place.
  - You know what records you have.
  - You can find what's needed easily.
  - Someone else can find what's needed if you are not there.

Start by sorting information into piles.

- Examples of piles are a health pile, school pile, legal pile, etc.
- If a pile has a lot of information, sort it into smaller piles. For example, sort school pile by each school year.

Decide where to put the records once they are sorted. Options include:

- Keep records in files, pocket folders, binders, plastic boxes, or file drawers.
- Scan and save records on a computer, USB flash drive, CD, or smart phone.
- Scan and save records using an online PHR service or "patient portal."

Tell others living in your home where PHR is in case it is needed quickly

## Tips for Organizing PHR

Organize your child's PHR so it's useful to you. Some ideas for organizing records are listed below.

- Choose a filing system such as:
  - 3-ring binder.
  - Accordion file.
  - File folders in a file drawer.
  - Online PHR storage.
- Use labels or binder tabs to write what is in each section.
- Choose a color for each type of information. For example:
  - Use red folders for health information and yellow for school records.
  - Use colored markers to label tabs in a binder.
- Make sure everything has a date.
- Keep the newest records in front.

# Take Action

## Keep Personal Health Record (PHR) Up To Date

Make a plan to keep PHR up to date. For example:

- Get copies of medical records every 6-months.
- Add new information to PHR as soon as possible after getting it.
- Ask providers to copy you on clinic notes and other records.
- Ask schools for copies of health and education plans.
- Get a copy of your health insurance policy whenever it changes.

Give records to providers, schools and others when needed. Make a portable PHR for clinic visits, meetings, and hospital stays.

- It takes time to gather missing information and records.
- You can help health care providers, schools and others by sharing records in PHR.
- Get a binder or folder for keeping the portable PHR.

Decide what records to keep in portable PHR. Examples are:

- The most recent medical and school records.
- Emergency information and clinical summary.
- Medicine list, immunization record, family history.
- Power of health care attorney and guardianship papers.

Plan ahead.

- Ask what records to bring before appointments and meetings.
- Get records that provider needs if you don't already have them.
- Never give away your only copy of a health record.
- Ask providers to copy the records they need.
- Make sure providers return your records to you.
- Keep portable PHR in an easy-to-reach place.
- Tell others living with you where to find portable PHR in case of an emergency.

## Getting Records for Continued Care

Sometimes you need copies of records for continued care. For example, you may need to share with a new doctor, school, or public insurance provider.

Don't wait until the last minute.

- Getting copies may take 1-2 months.
- Tell providers that you need copies by a certain date.
- Ask providers when copies will be ready.

Decide how to send the records to the provider who needs them.

- Pick them up and take to the provider.
- Have them mailed to the provider.

When you want records sent to a provider:

- Make sure you have the provider's address and phone number.
- Follow up to make sure records were received.

Make sure you say you need copies for continued care. You usually won't have to pay when that's the reason.

# Check Yourself



- I keep a Personal Health Record (PHR).
  - I know how to get copies of medical and other health records.
  - I have copies of important medical records.
  - I know how to get copies of school records.
  - I have copies of important school records.
  
- I keep the PHR organized.
  - It's easy to find the record I want.
  
- I keep PHR up to date.
  - I have a system or plan for keeping PHR up to date.
  
- I give records to providers, schools and others when needed.
  - I have a portable PHR for taking records to meetings and appointments.
  - I keep the portable PHR up to date.



# More Information and Resources

Ask your health care team when you have questions.  
They are your best resource.

**Audio Tapes** Quick messages about health information.

- **A personal story about keeping a PHR:** [http://www.myphr.com/about\\_stories.asp](http://www.myphr.com/about_stories.asp)
- **Keeping a PHR for your child:** <http://www.healthychildren.org/English/family-life/health-management/pages/Maintaining-a-Medical-Record.aspx>
- **Keeping health information private:** <http://www.healthychildren.org/English/family-life/health-management/pages/Privacy-of-Medical-Records.aspx>

**Online PHR Tools** Online PHR tools allow you to store and update health information. You can see and print the records from any computer with internet access. Some free PHR tools are:

- **Google Health:** <http://www.google.com/intl/en/options/> and click on “Google Health.”
- **Health Vault:** <http://www.healthvault.com/>
- **Children’s Hospital of Wisconsin’s Family Portal:** <https://familyportal.chw.org>
- **Surgeon General’s Family History Tool:** [www.familyhistory.hhs.gov](http://www.familyhistory.hhs.gov)
- Ask your employer, hospital, or health insurance provider if they offer online PHR storage.

## HIPAA Information

- **Health Privacy 101:** [http://www.cdt.org/healthprivacy/2008\\_HP101.pdf](http://www.cdt.org/healthprivacy/2008_HP101.pdf)
- **U.S. Dept. of Health and Human Services, Understanding HIPAA:** <http://www.hhs.gov/ocr/privacy/hipaa/understanding/>
- **Information about HIPAA and how to file a complaint:** [www.hhs.gov/ocr/hipaa/](http://www.hhs.gov/ocr/hipaa/)
- **To find your state Attorney General for complaints about HIPAA:** [http://www.naag.org/attorneys\\_general.php](http://www.naag.org/attorneys_general.php)

## FERPA Information

- **US Department of Education, Information about FERPA and how to file a complaint:**  
<http://www2.ed.gov/policy/gen/guid/fpco/ferpa/parents.html>

# Personal Health Records Forms

| <b>Form Name</b>   | <b>How it can be used</b>   |
|--|---|
| <b>Permission to Use and Share Patient Health Care Information</b> | This form gives permission to share health information and make copies of records . Usually doctors, clinics, and hospitals have their own form. They can mail or fax it to you. You can also pick it up. Use this form if a health care provider does not have their own form. |
| <b>School Contact List</b>   | Use this form to keep track of school employees working with your child. You may not have names to put in every space. Make sure to update the contact list each school year.   |
| <b>Health Record Checklist</b>                                     | Use this checklist as a guide. Decide what health records you want to put in Personal Health Record (PHR). You may already have some of the records. Put a check next to any records you don't have but want to put in PHR.   |
| <b>School Record Checklist</b>                                     | Use this checklist as a guide. Decide what school records you want to put in PHR. You may already have some of the records. Put a check next to any records you don't have but want to put in PHR.  |

## Permission to Use and Share Patient Health Care Information

|                            |                |       |    |       |          |          |
|----------------------------|----------------|-------|----|-------|----------|----------|
| <b>Patient Information</b> |                |       |    |       |          |          |
| Name                       | Last           | First | MI | month | day      | year     |
| Address                    | Street address |       |    | City  | State    | Zip Code |
|                            | Birth Date     |       |    | Phone |          |          |
|                            |                |       |    | State | Zip Code |          |

|  |  |      |       |          |  |
|--|--|------|-------|----------|--|
| <b>Health care provider who has permission to share my health care information</b> |  |      |       |          |  |
| Name of health care provider   |  |      |       |          |  |
| Street address or PO Box   |  |      |       |          |  |
| Address  |  | City | State | Zip Code |  |

|   |  |      |       |          |  |
|---|--|------|-------|----------|--|
| <b>Health care provider who will receive my health care information</b> |  |      |       |          |  |
| Name of health care provider  |  |      |       |          |  |
| Street address or PO Box  |  |      |       |          |  |
| Address   |  | City | State | Zip Code |  |

|  |  |  |  |  |  |
|--|--|--|--|--|--|
| <b>How information may be used</b><br>(check all that apply)   |  |  |  |  |  |
| <input type="checkbox"/> Give to the health care provider (disclose)<br><input type="checkbox"/> Share back and forth (exchange) |  |  |  |  |  |

|  |   |           |   |   |
|--|---|-----------|---|---|
| <input type="checkbox"/> Share information from this time period |   | <b>OR</b> | <input type="checkbox"/> Share information from this date |   |
| From   | / | to        | /   | / |

|   |  |  |               |  |  |
|---|--|--|---------------|--|--|
| <b>I give permission to share the information checked below. (Check all that apply)</b> |  |  |               |  |  |
| <input type="checkbox"/> Discharge summary  | <input type="checkbox"/> Lab result(s)                       | <input type="checkbox"/> Radiology result(s)     |               |  |  |
| <input type="checkbox"/> History and Physical(s)  | <input type="checkbox"/> Pathology result(s)                 | <input type="checkbox"/> Radiology film(s)       |               |  |  |
| <input type="checkbox"/> Operative report(s)  | <input type="checkbox"/> Pathology slide(s)                  | <input type="checkbox"/> EEG/EKG report(s)       |               |  |  |
| <input type="checkbox"/> Emergency report(s)  | <input type="checkbox"/> Genetic testing                     | <input type="checkbox"/> Clinic letters/notes    | From date(s): |  |  |
| <input type="checkbox"/> Consultation report(s)   | <input type="checkbox"/> Therapy report (s) (PT, OT, Speech) | <input type="checkbox"/> Complete hospital chart |               |  |  |
| <input type="checkbox"/> Growth Chart   | <input type="checkbox"/> Urgent Care report(s)               |  |               |  |  |
| <input type="checkbox"/> Other (please explain)   |  |  |               |  |  |
| <input type="checkbox"/> Other (please explain)   |  |  |               |  |  |

|  |   |  |  |  |  |
|--|---|--|--|--|--|
| <b>I give permission to share the information checked below. (Check and put initials next to all that apply)</b> |   |  |  |  |  |
| <input type="checkbox"/> HIV test results  | <input type="checkbox"/> Alcohol/Drug Treatment | <input type="checkbox"/> Mental Health record(s) |  |  |  |
| <input type="checkbox"/> Sexually Transmitted Diseases   | <input type="checkbox"/> School report (IEP)    | <input type="checkbox"/> Disability report       |  |  |  |

|   |  |   |  |  |  |
|---|--|---|--|--|--|
| <b>How the information will be used</b>                 |  |   |  |  |  |
| <input type="checkbox"/> Insurance eligibility/benefits | <input type="checkbox"/> Personal Use        | <input type="checkbox"/> Continuation of medical care |  |  |  |
| <input type="checkbox"/> Verbal/phone communication     | <input type="checkbox"/> Military enlistment | <input type="checkbox"/> Referral                     | <input type="checkbox"/> Legal Investigation |  |  |
| Other (list)  |  |   |  |  |  |

|   |   |                                 |  |      |  |
|---|---|---------------------------------|--|------|--|
| <b>Share information by</b>   |   |                                 |  |      |  |
| <input type="checkbox"/> U.S. mail  | <input type="checkbox"/> I will pick up | <input type="checkbox"/> Verbal | <input type="checkbox"/> I will view on site |      |  |
| <b>Date when my permission ends</b>   |   |                                 |  |      |  |
| <i>My permission ends two years after I sign this form if I don't write a date.</i> |   |                                 |  |      |  |
|   |   | month                           | day  | year |  |

I understand that:

- I can cancel or end my permission at any time. I must write a letter to the health care provider who shared the information. My letter should say that I want to cancel permission to share health care information. My letter will not affect information that was shared before I cancelled my permission.
- I don't have to give my permission. If I don't it will not affect my health care, the cost of my care or insurance benefits.
- There is a chance that the provider gets the information will share it with another provider or person.
- A copy or fax of this form is just as good in law as the written permission I am signing today.

|  |  |             |       |     |      |
|--|--|-------------|-------|-----|------|
| <b>Signature</b>   |  | <b>Date</b> | month | day | year |
|  |  |             | /     | /   | /    |
| <b>Relationship</b>  |  |             |       |     |      |
| <input type="checkbox"/> Self <input type="checkbox"/> Parent/Legal Guardian <input type="checkbox"/> Other (please list): |  |             |       |     |      |
| <b>Witness Signature</b>   |  | <b>Date</b> | month | day | year |
|  |  |             | /     | /   | /    |
| <b>Relationship</b>  |  |             |       |     |      |

Name: \_\_\_\_\_

## School Contact List

| <b>School</b>  |               |       |         |             |
|--|---------------|-------|---------|-------------|
| Address  |               |       |         | School Year |
| Phone  | Fax           | Email | Website |             |
| <b>Teachers</b> <i>Regular and special education teachers.</i>   |               |       |         |             |
| Name   | Subject/Type  | Phone | Email   |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
| <b>Student Aides</b>   |               |       |         |             |
| Name   | How they help | Phone | Email   |             |
|  |               |       |         |             |
|  |               |       |         |             |
| <b>Related Services Staff</b> <i>PT, OT, Speech Therapist, etc. Not every child has all the related services listed.</i> |               |       |         |             |
| Name   | What they do  | Phone | Email   |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |
|  |               |       |         |             |

Name: \_\_\_\_\_

## School Contact List

| School Nurse and Health Room Staff            |                                 |               |       |       |
|---|---------------------------------|---------------|-------|-------|
| Name  | Care they give                  | Phone         | Email |       |
|   |                                 |               |       |       |
|   |                                 |               |       |       |
| Administrators and Other School Staff         |                                 |               |       |       |
| Name  | Role                            | Phone         | Email |       |
|   | School Principal                |               |       |       |
|   | School Secretary                |               |       |       |
|   | Attendance Secretary            |               |       |       |
|   | Special Education Administrator |               |       |       |
|   | Superintendent                  |               |       |       |
|   | School Social Worker            |               |       |       |
|   | School Guidance Counselor       |               |       |       |
|   |                                 |               |       |       |
|   |                                 |               |       |       |
| Bus Company/School Transportation Provider(s) |                                 |               |       |       |
| Name of Provider                              | Pick up time                    | Drop off time | Phone | Email |
|   |                                 |               |       |       |
|   |                                 |               |       |       |
| After School Care Provider(s)                 |                                 |               |       |       |
| Name of Provider                              | Pick up time                    | Drop off time | Phone | Email |
|   |                                 |               |       |       |
|   |                                 |               |       |       |

## Health Record Checklist

Talk with your child’s health care provider. Use this checklist to discuss what records you should have at home. You need to know the date of the records you want. If you don’t know, write down your best guess, such as “Between 2007 and 2009.”

| Check if Needed          | Type of Information  | Report Date(s) |
|--------------------------|--|----------------|
| <input type="checkbox"/> | Information about health condition   |                |
| <input type="checkbox"/> | Clinical Summary   |                |
| <input type="checkbox"/> | Medicine List  |                |
| <input type="checkbox"/> | Immunization Records   |                |
| <input type="checkbox"/> | Family History Information   |                |
| <input type="checkbox"/> | Emergency Information Form   |                |
| <input type="checkbox"/> | Emergency Care Records   |                |
| <input type="checkbox"/> | Urgent Care Records  |                |
| <input type="checkbox"/> | Clinic Letters and Notes   |                |
| <input type="checkbox"/> | Notes from primary care doctor   |                |
| <input type="checkbox"/> | Consult Reports from specialty doctors   |                |
| <input type="checkbox"/> | Hospital Discharge Summary   |                |
| <input type="checkbox"/> | Surgery Reports (also called Operative Reports)  |                |
| <input type="checkbox"/> | Lab Results  |                |
| <input type="checkbox"/> | Pathology Results (for example, biopsy report)   |                |
| <input type="checkbox"/> | Imaging Results (x-rays, MRI, CT scan, etc.)<br>Results may be in writing and/or picture form. |                |
| <input type="checkbox"/> | Other Testing Results  |                |
| <input type="checkbox"/> | Therapy Reports (PT, OT, psychology, etc.)   |                |
| <input type="checkbox"/> | Home Health Care Notes (Get copies from Home Health Care Company)                              |                |
| <input type="checkbox"/> | School Health Records (Get copies from school)   |                |
| <input type="checkbox"/> | Health Care Provider Contact Information   |                |
| <input type="checkbox"/> |  |                |
| <input type="checkbox"/> |  |                |
| <input type="checkbox"/> |  |                |

## School Record Checklist

Use this checklist to decide what school records you should have at home. You need to know the date of the records you want. If you don't know, write down your best guess, such as "Second Grade."

| Check if needed   | Type of Information  | Report Date(s) |
|---|--|----------------|
| <b>General Information</b>  |  |                |
| <input type="checkbox"/>  | School contact list. List names, roles and contact information for all school staff members working with your child. |                |
| <input type="checkbox"/>  | Annual school handbook.  |                |
| <input type="checkbox"/>  | Report cards and progress reports.   |                |
| <input type="checkbox"/>  |  |                |
| <input type="checkbox"/>  |  |                |
| <input type="checkbox"/>  |  |                |
| <b>Tests and Evaluations</b>  |  |                |
| <input type="checkbox"/>  | School evaluation reports.   |                |
| <input type="checkbox"/>  | Copies of independent evaluations. Evaluations done by providers who do not work for school district.                |                |
| <input type="checkbox"/>  | Copies of any standardized or important test results.  |                |
| <input type="checkbox"/>  |  |                |
| <input type="checkbox"/>  |  |                |
| <b>Individualized Family Service Plan (IFSP), Individualized Education Plan (IEP), Section 504 Plan</b> |  |                |
| <input type="checkbox"/>  | Most current IEP, IFSP, or 504 Plan  |                |
| <input type="checkbox"/>  | At least the past two IEP, IFSP, and 504 Plan documents  |                |
| <input type="checkbox"/>  | IEP and IFSP progress reports  |                |
| <input type="checkbox"/>  | "Procedural Safeguard Notice." Information about a child's special education rights.                                 |                |
| <input type="checkbox"/>  | Dated notes about IEP and IFSP meetings and parent-teacher conferences   |                |
| <input type="checkbox"/>  |  |                |
| <input type="checkbox"/>  |  |                |

## School Record Checklist

| Check if needed              | Type of Information  | Report Date(s) |
|------------------------------|--|----------------|
| <b>School Health Records</b> |  |                |
| <input type="checkbox"/>     | Individualized Health Plan (IHP)   |                |
| <input type="checkbox"/>     | School Emergency Plan for child  |                |
| <input type="checkbox"/>     | Copies of signed physician orders about your child   |                |
| <input type="checkbox"/>     | List of medications that your child gets in school   |                |
| <input type="checkbox"/>     | Adaptive Physical Education notes  |                |
| <input type="checkbox"/>     | Written procedures for your child, e.g., feeding instructions.   |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <b>Communication Records</b> |  |                |
| <input type="checkbox"/>     | Dated notes about conversations with school staff, e.g., notes from a phone call about your child.       |                |
| <input type="checkbox"/>     | Written (email, hard copy, or hand written) letters and notes to and from school staff about your child. |                |
| <input type="checkbox"/>     | Behavior reports (suspensions, detention, etc.)  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <b>Other School Records</b>  |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |
| <input type="checkbox"/>     |  |                |