

Getting Started on a Portable Health Record or Personal Health Record (PHR) for Children or Adults with Genetic Conditions

Families, doctors and genetic counselors in the Western States Genetic Services Collaborative created a **Portable Health Record (PHR)** form for children, youth or adults with genetic conditions. People who have an ongoing health condition, or parents of children with special health care needs, have learned it is useful, efficient and can help with safe care to keep an up-to-date PHR. The PHR changes over time and is kept up-to-date by both you and your doctor, working together in partnership. Below, we use the word “you” or “your” when talking about the PHR. For parents, “you” or “your” may refer to your child’s PHR.

What is a PHR?

A PHR keeps important information about your or your child’s health in one place, ready to use when health care providers need up-to-date information for safe treatment or care. You may hear about both Personal Health Records and Portable Health Records. A Portable Health Record may be shorter than a complete Personal Health Record. The word “Portable” means the information can travel with you, or you or healthcare providers can get to the information wherever you are. The PHR can include emergency contact information, medical conditions, medicines, allergies, equipment, special instructions or any information someone would need to treat you or help with your care. You and your doctor can decide what to include.

Where do I keep my PHR?

There are several ways to keep a copy of your PHR.

1. **On paper.** You will need to update and keep copies where you can easily get to them.
2. **On a website.** Your doctor or insurance company may use electronic health records (EHR) and tell you how to keep your own PHR on a website they maintain. Or, you may use a free, public EHR website such as Microsoft Health Vault or Google Health.
3. **On a flash drive or CD.** A flash drive is a small device that can store and transfer information from one computer to another. Some hospitals and doctor’s offices do not want to use a patient’s flash drive or CD because these objects may transmit computer viruses.

When do I use my PHR?

1. **Emergency or travel.** When going to the Emergency Department or during a local emergency situation such as a power outage, flood, or earthquake, providers will have immediate information about your needs.
2. **Care coordination.** When updating or reviewing my Care Plan with my doctors, other healthcare providers, or with new doctors and providers.
3. **Community Sites or New Residence.** Staff at schools, camps, child care and adult care sites can use the PHR to learn about your health, assistance and safety needs.
4. **Family Use.** Using a PHR can help parents, spouses or other family members who help with your care keep track of your health and safety needs and be ready to share that information with providers if you are not able to.

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Portable Health Record for Children, Youth or Adults with Genetic Conditions

Date form completed	By Whom	Revised	Initials
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Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names and Relationship:		
Primary Language:	Other Phone Numbers:		
How I Communicate:	Who Makes My Health Decisions:		
<i>See page 6 for more information</i>			
Email Address:	Where I Have Received Most of My Care:		

Alerts/Physician Recommendations (Physician Signature: _____)

In an Emergency, do the Following:			
1.	3.		
2.	4.		
Allergies, Medications/Foods to be Avoided:			
1.	3.		
2.	4.		
Procedures to be Avoided			
1.	3.		
2.	4.		

Physicians:

Primary Care Physician:	Office or Emergency Phone:
	Fax:
Current Metabolic Specialist:	Office or Emergency Phone:
	Fax:
Current Geneticist:	Office or Emergency Phone:
	Fax:
Current Nutritionist:	Office or Emergency Phone:
	Fax:
Current Endocrinologist:	Office or Emergency Phone:
	Fax:
Other Specialist:	Office or Emergency Phone:
	Fax:
Other Specialist:	Office or Emergency Phone:
	Fax:

Diagnoses

1.	Age at Diagnosis:
	Who Made Diagnosis:
	Relevant/Recent Lab Tests:
2.	Age at Diagnosis:
	Who Made Diagnosis:
	Relevant/Recent Lab Tests:
3.	Age at Diagnosis:
	Who Made Diagnosis:
	Relevant/Recent Lab Tests:
4.	Age at Diagnosis:
	Who Made Diagnosis:
	Relevant/Recent Lab Test

Current Physical Condition of Individual

Baseline Physical Findings: Date:	Other Lab Findings: Date:
Baseline Vital Signs: Date:	Imaging Findings: Date:
Baseline Neurological Status: Date:	Other Significant Findings: Date:

Medications, Foods, Formulas, and Supplements

Medications:	
1.	Dosage Amount/Other Information
2.	Dosage Amount/Other Information
3.	Dosage Amount/Other Information
4.	Dosage Amount/Other Information
5.	Dosage Amount/Other Information
6.	Dosage Amount/Other Information
7.	Dosage Amount/Other Information
8.	Dosage Amount/Other Information
9.	Dosage Amount/Other Information

Medical Foods and Formulas:	
1.	Amount/Other Information
2.	Amount/Other Information
3.	Amount/Other Information
4.	Amount/Other Information
Vitamins and Other Supplements:	
1.	Amount/Other Information
2.	Amount/Other Information
3.	Amount/Other Information
4.	Amount/Other Information
Other Nutritional Accommodations:	
1.	3.
2.	4.

Surgeries

Past Surgical Procedures	
1. Date:	3. Date:
2. Date:	4. Date:

Other Management Information

Prostheses/Appliances/Surgical Implants:	Assistive Technology Devices:
1.	1.
2.	2.
3.	3.
Other Management Information:	
1.	
2.	
3.	

Common Health Concerns with Suggested Management

Problem	Suggested Diagnostic Studies	Treatment Considerations

Behaviors and Communication

People, places, or situations that cause happiness:	This is how I show I am happy:
People, places, or situations that cause anger, sadness, or frustration:	This is how I show my anger:
If I am scared, this is how I react:	When I am scared, I need you to:

Comments on Child/Youth, Family, or Other Specific Medical Issues

Attachments Related to Condition or Treatment (e.g.: Standards of Care documents, important lab tests, summaries of the condition, etc.)

1.
2.
3.
4.
5.

Signature of Person
Completing Form: _____ Print Name: _____

Relationship to Youth/Child: _____

Physician/Provider Signature: _____ Print Name: _____