



Questions about Genetics? Ask an Expert!

This is one of our very favorite websites for families of children with genetic conditions. The goal of Genes in Life is to answer your questions about health and genetics. If they cannot answer them, they will show you where to go to get the answers you need.

Our staff recently asked: *“What do you recommend parents do when they suspect that their child’s developmental delays or disabilities are due to a genetic condition? If their doctor is unconvinced that screening is necessary, what should a parent’s course of action be?”*

We quickly received an answer from [Howard Levy MD, Ph.D](#) from Johns Hopkins University. [Read his thoughtful answer here.](#) Dr. Levy is one of several genetics experts who will respond to questions. You may ask the Genes in Life experts whatever is on your mind. All the experts have broad knowledge about genetics and health. Of course, don’t use Genes In Life if you have an urgent health-related question; consult your doctor.



FAST FACT:

Only 7% of Oregon children with special health care needs (CSHCN) do not have a usual source of care when sick compared to 9.5% of CSHCN nationally.

Learn more: www.childhealthdata.org



Contact the

[Oregon Family to Family Health Information Center](#) at

1-855-323-6744



[Stay in touch by joining our mailing list!](#)

Emergency Preparedness and Children with Disabilities It’s a big job to prepare, but remember: *Some plan is better than no plan!*

Earthquakes, fire, and floods present real challenges for the millions of families of children with disabilities. Do you know what you would do in the case of an emergency? The Oregon Office on Disability and Health (OODH) at OHSU, in partnership with state and national emergency preparedness experts, has developed *Ready Now!* a [step-by-step guide](#) to help you prepare for an emergency.



Here are a few of the highlights:

- Know **what kind of emergencies** could happen in your area.
- Know the **problem areas** that may keep you from safely leaving a building during an emergency.
- Make an **emergency supply kit**, including food, water, first aid kit, adaptive equipment, batteries and supplies for you and your pets and service animals.
- Make a **medical information list** with medications, dosages, medical conditions and doctors contact information.
- Teach your children **safe places to go** during an emergency.
- Try and keep a **seven-day supply of medications** your family depends on.
- Make an emergency **information list** so others know whom to call for you if you need additional assistance.
- Install **smoke alarms** on each floor of your home. Know where controls for water, electricity, gas and sewer are and how to turn them off.

The OODH’s Emergency Guide is 127 pages of easy-to-use forms, information and instructions about how to tackle the job of preparing for an emergency. For more information and to download the guide, visit the [OODH website](#). If you do not use the internet and would like a copy of the guide, call (503) 494-1205.

Face to Face with your Child’s Doctor? *Tell your story quickly and clearly!*

You may have just a few minutes to explain your concerns. Here are some ideas to get the most from your appointment.



- **Tell all.** Remember to include all of your child’s symptoms. Even ones you may think are unrelated.
- **Make a timeline.** If you can remember the order your child’s symptoms appeared, jot it down and bring it with you.
- **Be specific.** Describe your child’s symptoms very specifically. For example, instead of saying “*he’s been vomiting all day,*” say “*he vomited 10 minutes after breakfast, two times after lunch, again just before dinner, and once on the drive here.*”
- **Tell it like it is.** Don’t minimize or exaggerate your concerns. Don’t avoid telling your doctor symptoms that may embarrass you. Be honest answering all questions.

This information was adapted with permission from the Consumer Reports tip sheet for adults entitled “[Communicating with Your Doctor.](#)” If you would like a copy of this article and do not have internet access, contact us at 855-323-6744.

Portland State University's Autism Diagnosis Project



Researchers at PSU's Autism Training and Research Center are looking for families and medical providers from around the state to fill out a survey for their **Autism Diagnosis Project**.

This purpose of the research is to:

- Learn what getting an Autism diagnosis for a child is like for parents
- Learn about how doctors make an Autism diagnosis
- Help children with Autism get a diagnosis and services at school earlier
- Create resources to help make diagnosing Autism easier for parents and doctors

Helping out is easy. Just fill out the [survey for parents](#) or the [survey for doctors](#).

They will only be able to see the date and time the survey was filled out and answers to each questions. Your name and contact information will not be asked.

Questions?

If you have questions about the **Autism Diagnosis Project**, please call Helen Young at 503-725-8009 or email her at autism@pdx.edu.



Alternate Newsletter Formats Available Upon Request



Families of children with special needs who do not have internet access may receive this newsletter by mail by calling **1-855-323-6744**.

Moving from the Pediatrician to an Adult Health Care Setting: Where do you start?

Families who enjoy a good relationship with their child's pediatrician face a dilemma once their child nears adulthood. Although some pediatricians are happy to keep seeing young adults with special needs past the age of 18, many parents and youth feel its time to make the transition to a more adult-oriented primary care provider. Some parents report that their twenty-something sons and daughters feel awkward going to a pediatric office "where the toys are". Some pediatricians, too, report that although they enjoy the relationship, that they are not best suited for treating adults.



Finding a General Practitioner or Internist who will care for your young adult with a special health condition may take some time, so start thinking about it when your child reaches his teens. Here are some ideas for finding a new doctor that experienced parents and teens recommend:

- Ask your current pediatrician or others in the pediatric practice for a referral
- Consider your personal doctor or the doctor of other friends and family
- Ask families from a family support group. Don't limit yourself to asking only families of children with a similar condition.
- Refer to your health insurance company booklet of approved providers.
- Ask at the agencies and organizations your child uses, such as Vocational Rehabilitation, Brokerage, or Independent Living Center.

There are many other ideas for finding a general practitioner for your son or daughter, and the OR F2F HIC parents will be happy to coach you in the steps of making a smooth transition. To make an appointment to talk about transition to adult care, call 855-323-6744. Leave a message stating that you would like transition assistance and the county you live in. Someone will return your call within two business days.

DID YOU KNOW? Fewer than half of Oregon youth with special health care needs receive the health care transition supports and services they need? Read more: [2009-10 National Survey of Children with Special Health Care Needs](#).

Getting to Know the ISP and PCP Process in Oregon

By Guest Author, Jennifer Allison, OTAC

The annual Individual Support Plan (also known as an ISP) is different and separate from the Individual Education Plan (IEP). Your child's IEP is about what your child needs to be successful in school, but an ISP looks at many other areas of your child's life. An ISP, for example, may list goals for jobs, housing, relationships, skill building, safety, independence, etc.

At this time, adults and children who are served through County Developmental Disability Services or Brokerages have an ISP. The ISP is typically completed by the child, youth, or adult and his or her DD Service Coordinator or Brokerage Personal Agent. A parent or other supportive person may also help write the plan.

Those who do not receive DD or Brokerage services may want to consider making a Person-Centered Plan. A PCP is similar to an ISP. A PCP can be written at any age. It gives the youth and his/her family a place to list skills, consider risks, and note helpful services. Most important, however, is that it celebrates the person's capabilities, and identifies the support they may need to achieve their future dreams.

The [Oregon Technical Assistance Corporation](#), as well as many other organizations and parent networks, can help someone make a person-centered individual support plan. Read more about Person-Centered Plans at [OTAC](#) or [FACT](#) or [The Arc's](#) websites. Read more about [Individual Support Plans](#) here. If you would like information mailed to you, contact us at 855-323-6744.



The resources on this page are not comprehensive nor does inclusion imply endorsement by the Oregon F2F HIC or the Oregon Health & Science University (OHSU). These resources are intended to be a starting point for further research. The Oregon F2F HIC is a family-led effort, funded by a grant from the Health Resources and Services Administration/Maternal and Child Health Bureau. The F2F is closely affiliated with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), located at the Institute on Development & Disability (IDD) at OHSU.