



### Flu & Kids with Special Health Needs: A Warning

Flu season begins October 1, and this year we have some concerning information about how flu can be extra dangerous for our children with special health needs. The Centers for Disease Control and Prevention (CDC), worked with Family Voices and F2F HICs last year to gather information about how flu affects families of kids with disabilities. They found that:

- Only half of children with neurologic and neurodevelopmental conditions are vaccinated against the flu each year.
- While families view their child's doctor as the main source of information about the flu, many pediatricians do not recognize intellectual disability as a high-risk condition for the flu.
- 64% of children with underlying health conditions who died from the flu had a neurologic disorder or neurodevelopmental condition.

**Call to Action:** Families and health care providers must both learn about the potentially serious complications of the flu for children with special health needs and take steps to prevent avoidable illness. Families can:

- Follow the [CDC guidelines](#) that anyone over the age of 6 months get a flu shot.
- Copy and share [this letter](#) from the CDC with their pediatricians to help him/her understand the risk to our children with neurologic and neurodevelopmental conditions.

#### FAST FACT:

Nearly 30% of Oregon children with special health care needs (CSHCN) compared to 24% of CSHCN nationwide have an unmet need for specific health care services.

Learn more: [www.childhealthdata.org](http://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!](#)**

### This Project Shouldn't Wait: Make Your Child's Emergency Plan

*Thank you to the American Academy of Pediatrics and the American College of Emergency Physicians for this free, easy to use resource.*

Children with special health care needs have 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 AAP and the ACEP have developed the Emergency Information Form. Instructions:

1. **Get the form.** [Click here](#), or call the OR F2F HIC to have one mailed to you.
2. **Fill it out to the best of your ability.** Take it to your child's primary care doctor to fill out the parts you cannot.
3. **Make several copies and distribute to:**
  - DOCTORS: On file with each of the child's physicians, including specialists.
  - ER: On file with the local emergency rooms where the child is most likely to be treated in the case of an emergency.
  - YOUR HOME: in a place where it can be easily found, such as the refrigerator.
  - YOUR CARS: In each parent's vehicle (i.e., glove box).
  - WORK: At each parent's workplace.
  - PURSE/WALLET: In each parent's purse or wallet.
  - SCHOOL: On file with the child's school, such as in the school nurse's office.
  - CHILD'S BELONGINGS: Backpack, or suitcase when traveling
  - EMERGENCY CONTACT PERSON: At the home of your emergency contact person
4. **Register:** Consider registering your child with MedicAlert®. Send MedicAlert® 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, or ANYTIME there has been a change in your child's condition, physicians, treatment plan, or if your child has had a major procedure.

### Oregon Families Can Receive a Free Copy of This Great Family Pocket Guide

This colorful 158-page book has great articles by families and doctors on raising healthy babies, children, and teens.

For ordering (including bulk orders) go to: [Family Voices website](#) or call us to request a copy!



### People First Language—No More “R” Word

The Social Security Administration is the latest federal agency to start using the term “intellectual disability” instead of “mental retardation.” Under the new rule, all references to “mental retardation” and “mentally retarded children” will be replaced with “intellectual disability” and “children with intellectual disability” within Social Security's Listing of Impairments and other agency rules. The change will not impact how claims are evaluated for those with the developmental disability. Kudos to the SSA!

Download the poster “Some Words Do Hurt” at the [Oregon Council on Developmental Disabilities](#) and read more about People First Language at [Disability is Natural](#). Call us for reprints of this information if you don't have access to a computer.

## Free Resources for Families!

### Meet my Child

The National Center for Learning Disabilities has published a great Resource for kids (either with or without special needs) who are headed off to school for the first time. In this free booklet, you can explain the kinds of therapy your child receives, how he or she learns best, his talents, quirks, and much more! [Download here](#), or call us for a printed copy!



### Personalized Planning for Your Child's Next Doctor's Appointment

Its hard to remember all of your questions when taking our kids to the doctor! Use this free, online activity to plan your next visit. This planner can be used whether or not your child has special needs. When you have completed it, you can print out a planning guide to take to the appointment. If your child is under age three, [try it here!](#) If you would like to try the planner but don't use the internet, we can do it with you by phone! Call the OR F2F HIC at 1-855-323-6744.



### 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.*

## Facts and Myths about the Affordable Care Act

There are some myths and misunderstandings about what the new Affordable Care Act will mean to families. This month, we'll try to clear up two of them:

### Myth: The Affordable Care Act created a new government-run-insurance plan.

**Fact:** There is no "government-run" plan, but the federal government has provided start-up funds for states to open "Marketplaces" through which everyone can buy insurance. In Oregon, our Marketplace is called "Cover Oregon" and it opens on October 1. Families will be able to shop for insurance plans, and will have a lot of options to choose from. Any plan sold through the marketplace will have met guidelines and it will be easy to compare plans and prices from several companies. Through the Marketplace, you will be able to have a certified agent help you make decisions on the kind of insurance that works best for your family, especially if you have children with special needs.



The government is also giving tax credits and co-pay assistance to lower-income families to help them afford insurance. And for those who have very little income, Medicaid (The Oregon Health Plan) will be easier to get.

### Myth: In 2014, everyone has to buy insurance or pay a penalty

**Fact:** Those who have insurance through their job, Medicare, the military, the veteran's administration, or their school will not have to shop for insurance or pay a penalty. Other exemptions include: those who are not required to file taxes, those belonging to established congregations that do not believe in insurance, members of American Indian tribes, members of Health Care Sharing Ministries, and incarcerated individuals. More info: [www.health.care.gov](http://www.health.care.gov)

## Congratulations to Oregon's New Family Scholar!



Tami Montemayor, our Family Liaison in Marion County, was recently selected to attend the prestigious Family Scholar Program. This ten-month course of study, based in Washington, DC, is a program of the Association of Maternal and Child Health Programs. Tami will work with parent leaders from around the country to promote policies that effect our children. Tami and her husband Louis Montemayor are the proud parents of Gabriel, who starts kindergarten this year!

## Welcome New Parent Liaison—Signe Miller

We are pleased to announce that Signe (pronounced See-na) Miller will be the new Family Liaison serving Lincoln County. In addition to working with the OR F2F HIC, Signe works with the Community Connections Team there. Signe also works with the Oregon Family Support Network, and is very knowledgeable about the mental health systems of care for kids. Signe can be reached at [millesi@ohsu.edu](mailto:millesi@ohsu.edu). Welcome Signe!

*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.*