

Title V Has a New Web Site

Claire Tranchese

Find out more about us. Discover community resources that will work for you.

Connect with other families of children with special health needs.

www.ohsu.edu/outreach/cdrc/oscsnh/

Many things have been going on in the Title V office at CDRC. We take part in so many different activities that it is hard, even for us, to keep track of what we are all doing. We understand how important it is to keep our partners and those we serve aware of what we are doing and informed of the programs and resources we have to offer. After a year of development, we have launched our new web site.

This new web site has plentiful information about the many programs and projects we are working on. We provide information and local contacts for our community-based programs throughout Oregon. We share stories, information and support programs for families. We give providers around the state

information about our programs and how they can benefit from them. We have begun to collect and disseminate information about resources and data that we have to offer as well as other services available around the state. We also provide an overview of who we are, what we do, and how we are doing it.

We hope that you will begin to use our site as a resource for children, youth and families around the state. Our site will remain dynamic and have the most up-to-date information available. We appreciate any comments or concerns you may have, so do not hesitate to contact us. We need our audience to help us make this the best, most user-friendly site that we can.

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HEALTHY WEB SURFING: Evaluating Health Information on the Web

There is a tremendous amount of information about specific health conditions on the internet. It is often difficult to evaluate the accuracy and usefulness of the content. Many websites provide valuable information while others may have information that is unreliable or misleading.

There are guidelines for evaluating sites and the information they provide. Two helpful guides are **10 Things To Know About Evaluating Medical Resources on the Web** (reprinted on page 5 below) and the **MEDLINEplus Guide to Healthy Web Surfing**. Both are provided by the National Library of Health and are available at the National Institute of Health website: www.nlm.nih.gov.

Bob's Corner: *The Director is Usually In*

Dr. Robert Nickel, Director

Hi, there has been a lot of activity in the OSCSHN office since our last newsletter but I'd like to start on a personal note. I have stepped down as Director of the office as of July 1, 2005. I will maintain a commitment to the office as a medical consultant. When I assumed the Director's position last July I did not intend to leave in one year. My decision has nothing to do with my view of the increasing importance of public health or my esteem for public health professionals. I was married on July 16, and Ginger and I have moved from different directions to Eugene. Now on to other things.

We have a new name, the Oregon Center for Children and Youth with Special Health Needs. A great deal of the attention of center staff over the last few months has been directed towards completion of our statewide 5 year needs assessment and the rewrite of our section of the Title V Block Grant. We are soon to complete the final activities of our state needs assessment and continue to prioritize issues and plan for the activities of the center for the next 5 years. All of this will be described in detail in our portion of the Maternal and Child Health Bureau Block Grant application which will be accessible on the MCHB website in October, 2005. Thanks to all of you who have participated in the process. Recently we also have initiated 2 important activities: convening a statewide stakeholders group related to our national performance measure, "ensuring adequate financing of needed services;" and development of a universal application system in Oregon based on the Utah model.

Diane Smith is facilitating the stakeholders group on financing health services. Bobby Peterson of ABC for Health, a legal advocacy law firm in Wisconsin, chaired the first meeting and shared information about his program called "managed advocacy." Managed advocacy has three components: benefits counseling, training of staff, and coalition building. The stakeholders meeting was the first step in building a state coalition on this issue. We also hope to build local coalitions and develop a training program on managed advocacy which will become a regular part of our annual spring training. These 2 activities will be funded by our new integrated services grant, Strengthening Oregon's Community Services (SOCS), which is described below. The second meeting of the state stakeholders group will be in mid-September.

Staff from the Early Intervention Research Institute (EIRI) at Utah State University were here in April to describe Utah Clicks, a universal application system. This particular

activity addressed another national performance measure: "services will be organized so that families can access them easily." Through Utah Clicks, families can access information about public funded programs, submit demographic data, get information about programs for which they might be eligible, and then file an application on line if they chose to do so. We are currently working with staff from EIRI to develop Oregon Clicks. This universal application system initially will include the following programs; the OSCSHN office, WIC, Babies First, Early Intervention/Early childhood Special Education, and Medicaid (Oregon Medical Assistance Program). We hope to pilot test the system in 3 counties in January, 2006.

Finally, we are very pleased to report that our application for the MCHB integrated services grant, SOCS, was approved. Funding began on May 1, 2005, and will continue through April 30, 2008. This grant will provide \$ to support the training in managed advocacy, adding parents to professional teams (e.g., our Community Connections Network teams), small grants to the 6 county teams of the Youth Transition learning collaborative, and will fund a new learning collaborative on developmental and behavioral screening that will involve 5 community teams. We will be collaborating with the Oregon Rural Practice Research Network at OHSU in carrying out most of the activities in this grant.

Please email questions or comments: nickelr@ohsu.edu

CaCoon Program Nurse Consultant Position is Available

As many of you have heard, Judith Wickman, R.N., has resigned her position as Nurse Consultant for the CaCoon Program. Judy has, over the years, contributed to the overall effort of improving the lives of Oregon's children with special health needs. We will miss her insight and knowledge of care needs, training strategies and successful networking. We wish her well in her current pursuits and we look forward to working with her on special projects as her time allows.

We are currently recruiting for a Community Consultant to provide nursing consultation and community team support. If you are interested or know someone who might be, please contact me.

Diane Smith, Community-Based Services Manager
smithdi@ohsu.edu, 503-494-3210 or 1-877-307-7070

Voices of Families: Advocating for My Kids

By Wendy Bass



Jaimie at age 18 with Wendy

Sometimes we are confronted with the very things we fear we can't handle only to find that they stretch us beyond our limitations and we become a far better person for it. Raising two disabled children was my challenge. Advocacy was my extraordinary purpose. It was an amazing journey!

As a young person, I had very little exposure to people with disabilities and certainly no education about them. There was an "M.R." classroom at school, but the students were isolated and made fun of by most of the other kids. What I did see frightened me. Ignorance produced the fear. I didn't know anyone with a disability, personally. I had even vocalized that I could never deal with having a child with a handicap. When I became pregnant with my first child, it never crossed my mind that I would have anything other than a normal, healthy baby. I was wrong.

I did not realize at the time that my daughter Jaimie was born that she had a disability. I had no yardstick by which to measure her development. As she grew, the delays were more pronounced. I discovered that very little was known about her condition. No one had any answers as I aggressively sought treatment for my daughter. Even more disturbing was the lack of education and services in the educational setting for the severely challenged child. My life was filled with doctor appointments, therapy and early intervention.

I was on a constant quest to find answers. Services in the school system were limited at best. Jaimie had to be bused to another town one hour each way. Teachers didn't know what to do with her and I found myself having to monitor and question techniques used.

My second child was born with normal skills. The third child, Joel, had the same condition as Jaimie. At that point, we knew that their condition was genetic, although we didn't know what it was. I knew that I had to become the expert so I sought information from as many professionals and parents as I could. I joined advisory boards for the ARC, Early intervention, ESD, the Disability Council and Parent-to-Parent. I attended workshops, trainings and conferences. I met with lawmakers, attended IEP meetings and went to the hearings at the capital.

Joel attended our neighborhood school after attending a specialized school. I took it upon myself to educate the school district, students and teachers about him and his disability. I pushed for in-services for teachers and instructional assistants. I was confronted with the same fear and ignorance that I once possessed. People were resistant to change and money in school districts was tight. I had to be the squeaky wheel to get what I needed for my children.

However, educating the other children was a lot easier. Joel's presence took away their fear and minimized the differences. It benefited my son tremendously.

For the first time, Joel had friends. Students in his classroom learned to be compassionate and non-judgmental as well as inclusive. Parents of the other kids noticed the difference in their kids.



Joel at age 15

Continued on page 4

Continued from page 3

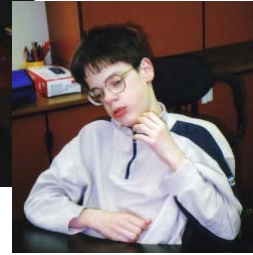
Finding myself in a situation that I had no control over, I was forced to confront my own fears. I learned that ignorance drives fear for many people. Life is seldom fair. Individuals with disabilities who cannot fight for their rights need a willing and interested voice.

Advocacy is hard work and not always appreciated by others. The bottom line is this: Is one life more valuable and deserving than another? How do you measure value? How do we measure someone's contribution to society? By virtue of being human, we have worth. It shouldn't matter how different we are. Those differences are what make life interesting and can ultimately contribute to the impact we have on others and our world.



Jaimie, age 19

Joel, 15 1/2



Jaimie died when she was 19. Joel died when he was 15 1/2. Both kids are survived by Mom, Dad, sister, and brother.

THANK YOU FAMILY SUPPORT PROGRAM and ZETOSCH

Kristi Trimbath

My son Turner is in a wheel chair. We needed to install a ramp desperately. I was breaking my back getting Turner's 100 lb wheelchair out of the house and down three steps to the school bus every day. That doesn't even count the times we needed to go to the doctor, grocery store or the hundreds of other errands we do every day. With three children and one income, we could not afford to put in a ramp on our own. Our insurance would not pay and our income is too high to qualify for public funds.

I was able to contact Pat from CDRC, have our Physical Therapist help fill out the paper work, get bids from contractors and apply for Family Support and Zetosh Funds. The contractor was flexible and very helpful in working with the OSCSHN Program.

This ramp really saved me physically. It also prevented potential injury to Turner. I know this is something parents go through all the time. It was great to have this help! We are very grateful.



Turner Trimbath using his new ramp

For information about funding through Title V, contact Patty Day or Pat Langston in the OSCSHN Office: 503-494-2765, 1-877-307-7070, dayp@ohsu.edu, langstop@ohsu.edu

Or visit our Website! www.ohsu.edu/outreach/cdrc/oscsnh/

Resource Fair October 13 Sponsored by Washington County DD

Sunset Presbyterian Church 14986 NW Cornell Road Portland OR 11:00- 4:00

For information, contact Nancy Milligan-Mock at Washington County Health & Human Services

Tel: 503-846-5749; email: nancy_milligan-mock@co.washington.or.us.

10 Things To Know About Evaluating Medical Resources on the Web

The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading. This short guide contains important questions you should consider as you look for health information online. Answering these questions when you visit a new site will help you evaluate the information you find.

Reprinted from the NCCAM website: www.nlm.nih.gov/medlineplus/healthywebsurfing

1. Who runs this site?

Any good health-related Web site should make it easy for you to learn who is responsible for the site and its information. On this site, for example, the National Center for Complementary and Alternative Medicine (NCCAM) is clearly marked on every major page of the site, along with a link to the NCCAM homepage.

2. Who pays for the site?

It costs money to run a Web site. The source of a Web site's funding should be clearly stated or readily apparent. For example, Web addresses ending in ".gov" denote a Federal Government-sponsored site. You should know how the site pays for its existence. Does it sell advertising? Is it sponsored by a drug company? The source of funding can affect what content is presented, how the content is presented, and what the site owners want to accomplish on the site.

3. What is the purpose of the site?

This question is related to who runs and pays for the site. An "About This Site" link appears on many sites; if it's there, use it. The purpose of the site should be clearly stated and should help you evaluate the trustworthiness of the information.

4. Where does the information come from?

Many health/medical sites post information collected from other Web sites or sources. If the person or organization in charge of the site did not create the information, the original source should be clearly labeled.

5. What is the basis of the information?

In addition to identifying who wrote the material you are reading, the site should describe the evidence that the material is based on. Medical facts and figures should have references (such as to articles in medical journals). Also, opinions or advice should be clearly set apart from information that is "evidence-based" (that is, based on research results).

6. How is the information selected?

Is there an editorial board? Do people with excellent professional and scientific qualifications review the material before it is posted?

7. How current is the information?

Web sites should be reviewed and updated on a regular basis.

It is particularly important that medical information be current. The most recent update or review date should be clearly posted. Even if the information has not changed, you want to know whether the site owners have reviewed it recently to ensure that it is still valid.

8. How does the site choose links to other sites?

Web sites usually have a policy about how they establish links to other sites. Some medical sites take a conservative approach and don't link to any other sites. Some link to any site that asks, or pays, for a link. Others only link to sites that have met certain criteria.

9. What information about you does the site collect, and why?

Web sites routinely track the paths visitors take through their sites to determine what pages are being used. However, many health Web sites ask for you to "subscribe" or "become a member." In some cases, this may be so that they can collect a user fee or select information for you that is relevant to your concerns. In all cases, this will give the site personal information about you. Any credible health site asking for this kind of information should tell you exactly what they will and will not do with it. Many commercial sites sell "aggregate" (collected) data about their users to other companies--information such as what percentage of their users are women with breast cancer, for example. In some cases they may collect and reuse information that is "personally identifiable," such as your ZIP code, gender, and birth date. Be certain that you read and understand any privacy policy or similar language on the site, and don't sign up for anything that you are not sure you fully understand.

10. How does the site manage interactions with visitors?

There should always be a way for you to contact the site owner if you run across problems or have questions or feedback. If the site hosts chat rooms or other online discussion areas, it should tell visitors what the terms of using this service are. Is it moderated? If so, by whom, and why? It is always a good idea to spend time reading the discussion without joining in, so that you feel comfortable with the environment before becoming a participant.

This publication is adapted from a fact sheet produced by the National Cancer Institute. It is not copyrighted and it is in the public domain. You can find it and other resources at: <http://nccam.nih.gov/health/webresources>

WEB RESOURCES

The National Library of Medicine (NLM) is the world's largest medical library. Located on the campus of the National Institute of Health (NIH) in Bethesda, Maryland, NLM collects materials and provides information and research services in all areas of biomedicine and health care. **MedlinePlus** is the NLM's web site for consumer health information. It is not an exhaustive list of every health web resource, but rather a selective list of authoritative health information sources from NIH and other government and professional organizations in the U.S.
www.nlm.nih.gov/medlineplus/

The Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association refers health consumers to resources and provides a list of the 100 Top recommendations with the goal of providing a limited number of resources that meet the quality criteria for currency, credibility, content, and audience. Some of the sites from the **"Top Ten" Most Useful Websites** with information relating to Special Health Needs are listed below.

<http://caphis.mlanet.org/> (**indicates Spanish/English)

Centers for Disease Control and Prevention (CDC)** www.cdc.gov

American Academy of Family Physicians** www.familydoctor.org

National Health Information Center** www.healthfinder.gov

Kidshealth® Kids with Special Needs** www.kidshealth.org/kid/feeling/friend/special_needs.html

MEDEM: an information partnership of medical societies** www.medem.com/MedLB/medlib

MEDLINEplus www.nlm.nih.gov/medlineplus/

NOAH: New York Online Access to Health www.noah-health.org

The Jean Baton Swindells Resource Center for Children and Families connects families, caregivers and friends of children with disabilities statewide to resources, information and training. Families come to the Swindells Center, call, or access the website seeking answers to many of the questions that surface in their everyday lives. Swindells offers resources specific to disabilities and conditions, as well as information on respite options, recreation, educational options, information in other languages and other day-to-day issues. Information about the Swindell Center is offered in Spanish. The Swindell Center is located in the Providence Parkrose Medical Plaza, 3510 NE 122nd Ave., Ste. 101, Portland OR 97230; Phone: 503-215-2429 or 800-833-8899, ext. 52429 swindells@providence.org
www.providence.org/Oregon/Programs_and_Services/ChildCenter/e15swindells.htm

Health Information in Other Languages

Oregon Health & Sciences University (OHSU) Links to Patient Education Materials provides English and non-English language sites and low-literacy handouts in both languages: <http://www.ohsu.edu/library/patiented/>

Knowledge Path: Spanish-Language Health Resources www.mchlibrary.info/KnowledgePaths/kp_spanish.html
This knowledge path has been compiled by the Maternal and Child Health (MCH) Library at Georgetown University. It points to recent, high-quality Spanish-language health resources for health professionals and consumers. While most of the resources cover a wide range of health topics, in each section there is a selection that focuses on topics of interest to families and professionals in the maternal and child health (MCH) community. This guide is updated periodically and there are related topics for health professionals, program administrators and policymakers in a bibliography, **Culturally competent services** (2003), that references materials about assessing services for cultural sensitivity, developing culturally sensitive materials, providing services in a multicultural health care context and additional resources about cultural competency and racial and ethnic disparities in health.

SPIRAL: Selected Patient Information Resources in Asian Languages <http://spiral.tufts.edu/>
SPIRAL is a new health information resource which provides a central source of health information through selected Web sites for Asian-language speakers and the professionals who serve them. It contains detailed health information in seven Asian languages: Chinese, Hmong, Khmer, Korean, Laotian, Thai and Vietnamese and in English so that an English-speaking physician or caregiver can see what patients are reading. Spiral is a joint initiative of the South Cove Community Health Center and Tufts University Health Sciences Library and is supported by a grant from the New England Region of the National Network of Libraries of Medicine.

Title V Annual Conference, May 2005

Mental Health & Behavioral Issues in Children

With Special Health Needs: Assessment and Strategies

Thank you to all the attendees at the Title V Annual Conference for helping to make the event such a success. This year's topic, Mental Health and Behavior Issues provided an opportunity for us to join with the Clackamas Partnership System of Care to bring family members and other health professionals together to share information. The two day event focused on screening and assessment of behavior problems. It presented ideas on designing behavior supports for children with a special focus on the student with chronic and high level needs. Useful screening and assessment checklists were shared, as well as tools to assist providers and families develop behavior support plans.

The Children's Mental Health System of Change Initiative was described highlighting areas of continued need, including parity in mental health services for all children. The concurrent sessions provided an opportunity for more detailed discussion based on age – infant, school age and adolescents.



Robert Nikkel, MSW, and Dr. Bob Nickel

Stories from families were the highlight of the event. A feeding panel of parents whose children have had a variety of feeding issues throughout life reminded us

how important it is to listen to what the child is communicating, to focus on the child first, and to incorporate methods and technologies appropriate for child and family. Parent consultant Theresa Rice teamed with Clackamas Partnership Director Diana Roberts to offer essential components for successful parent/health professional partnerships. Later, Teresa's son Cody joined her to provide a student and parent perspective.



Cody Rea and mother Theresa Rice, parent consultant with Family Involvement Network

The Cinco de Mayo networking activity at the end of the day was a wonderfully fun opportunity to network with our colleagues, debrief about the information presented during the day and to have a bit of fun.



Cinco de Mayo fun, food and conversation

If you missed this event, the checklist and reference materials are listed on the OSCSHN website at : www.ohsu.edu/outreach/cdrc/oscs hn/index.html.

...and mark your calendar for our upcoming training on Pain Management for Children with Special Health Needs on October 14 in Portland. <http://www.ohsu.edu/outreach/cdrc/oscs hn/resources/edopps.html>

Come hear experienced speakers on pain management for children and youth with special health needs.

Save the Date!
October 14, 2005

Oregon Services for Children with Special Health Needs
 Child Development and Rehabilitation Center
 Oregon Health & Science University
 707 SW Gaines Rd PO Box 574
 Portland, OR 97207-0574

Join us for a super conference packed with the latest information on the assessment and management of pain for children with special health needs. This conference is sponsored by Oregon Services for Children with Special Health Needs (OSCSHN) located at the Child Development and Rehabilitation Center at Oregon Health & Science University in Portland, Oregon. This statewide conference is intended for nurses, physicians, psychologists, occupational therapists, physical therapists and other allied health professionals. The conference will meet the nursing requirement for 6 hours of CEUs in pain management.

For more information, contact: **Nancy Lowry at 503.494.8360, lowryn@ohsu.edu**

Statewide Conference Ambridge Event Center Portland, Oregon

Please send us your E-mail address.

To save postage and printing cost, we want to send the newsletter to you electronically in a pdf format. If you have an E-mail address, please send it to Char Schley at schleyc@ohsu.edu.

If you wish to be taken off our newsletter mailing list, please contact Char by e-mail or phone:
 1-877-307-7070 x4-4587

We welcome your comments and submissions.

Deadline for submissions to the Winter edition is October 1st, 2005

Contact Information



Community Connections Network
 503-494-4586



CaCoon Care Coordination Program
 503-494-4219



Oregon Medical Home Project
 503-494-3232



FISHs: Framework for Integrating Special Health Services



FSP - Family Support Program
 503-494-8303



FIN - Family Involvement Network
 503-418-1476



SOCS - Strengthening Oregon Community Services
 504-494-3232

Toll Free: 1-877-307-7070

OSCSHN Office FAX: 503-494-2755

Web: www.ohsu.edu/outreach/cdrc/oscshn/

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