



Oregon Services for Children with Special Health Needs

A NEWSLETTER CONNECTING OUR COMMUNITIES

April 2004

In the first edition of the Title V Newsletter, we focused on the activities of the newer and less known programs of Title V: Oregon Medical Home Project, Family Involvement Network, Family Support Program and FISHS. Our core community-based programs, the Community Connections Network (CCN) and the CaCoon Program, consist of local agencies and providers who assess, consult, and coordinate care for special needs children and families. CCN and CaCoon provide the foundation for developing stronger systems of community-based services for families throughout Oregon.

COMMUNITY CONNECTIONS NETWORK (CCN):

CCN is a network of fifteen clinics serving 28 counties across Oregon that seeks to improve care for children with special health needs in the more rural areas of the state. Community providers from health, education and social services work together with the family and provide a team evaluation for children and young adults who have unresolved medical issues and/or for whom progress is not as expected.

Services include:

- reviewing prior evaluations
- interdisciplinary team evaluations, treatment recommendations
- team planning with families and local providers for meeting specialized needs
- modifying treatment recommendations based on local resources
- assessment of available services in the community
- linkage to community services, and
- periodic and long term follow-up

**Contact information: 503-494-4586
1-800-452-3563, x4586**

CACOON (CARE COORDINATION): CaCoon is

a statewide program that uses county public health nurses to work with families who have children with special health conditions to identify needs and locate appropriate services. These nurses provide specialized nursing interventions and help families coordinate their child's care. Services may be provided in the home, at local health departments, in hospitals or by phone consultation. Services include:

- child and family assessment and identification of health and resource needs
- linking the family to specialty health care and community resources
- assisting the family to understand and provide their child's special care
- monitoring child health and development to maximize potential and prevent secondary conditions
- support and counseling
- advocacy
- consultation and collaboration to facilitate teamwork among families, providers and community resources

In this Issue:

CCN Annual Conference2

Rural Health White Paper ...3

The CDRC Dental Clinic3

DENTAL RESOURCES.....4

CAMPS for Kids.....6

To access services, call the local county health department and ask for the CaCoon nurse, or contact the CaCoon nurse consultants in the Title V Office at CDRC:

503-494-4219

1-800-452-3563 x 4219

Community Connections Network Annual Conference



Dr. Tina Castañares, MD

The Edgefield Manor provided a fun and relaxing environment to catch up with friends and colleagues and to establish new connections. At a special social event, OSCSHN Assistant Director Catherine Renken and CCN Program Director Kathleen Williams were honored for their years of service and their dedication to children with special health care needs. As they retire, they leave a legacy of community support for Oregon children and families.



Kathie Williams and Cathy Renken

Thanks for your attendance!
We look forward to bringing together participants from all of the Title V programs at next year's conference.

The CCN Annual Conference, held April 8th and 9th at Edgefield Manor, was a great success! This year's conference heralded a new sense of collaboration for the Title V communities of Oregon with the attendance and shared learning of CaCoon nurses and CCN teams. Both groups were well represented, and a number of people from the Family Involvement Network, FISHS and Oregon Medical Home Program were also in attendance.

The speakers were excellent and very well received. Dr. Tina Castañares gave an engaging presentation on popular education and putting families first. Parents Leslee Child, Cathy Teal and Susana Rameriz spoke about the difficulties and rewards of being parents of children with special health needs.



Kathie Williams,
CCN Program Director

Dr. Brian Rogers spoke on coordinating services and providing feedback to families. He and Dr. Bob Nickel met with CCN physicians at lunch to discuss the challenges and opportunities of serving children and families as a team. They shared ideas for strengthening the collaborative relationship between communities and CDRC. University of Oregon educator, Dan Close spoke on the challenges and opportunities of adolescent transition.

Other highlights included presentations on pediatric sleep disorders, parent training for children with autism and communication disorders, genetic factors in developmental delay and mental retardation, sensory integration, and evaluation and management of behavior problems.

The CDRC Dental Clinic

Locating a Pediatric Dentist for children with special needs in Oregon communities may be difficult. There are few dentists who specialize in oral care for special needs children and very few practices outside the Portland Metropolitan area. Dr. Peter Lax provides specialized dental care on site at OHSU through the CDRC Dental Clinic, which cares for children from all parts of Oregon. The clinic may also be able to help locate a community provider. While the best way to locate a qualified dentist is to contact the patient's insurance carrier, clinic staff may have additional suggestions and can also advise families who have no insurance.



Dr. Peter Lax and Staff

Front from left: Kathy Vu, Admin Asst., and Mary Bravo, Dental Assistant. Back from left: Dr. Lax and Howard Wicklund, Admin. Asst. Not pictured: Hygienist Sherry Lemon

The CDRC Dental Clinic serves children and young adults to age 18 with disabling conditions. Cerebral palsy, autism, spina bifida and genetic conditions are examples of some of those disabilities. The clinic also manages the dental and oral health of children with cancer, congenital heart disease, and transplants.

In addition to Pediatric Dentist Peter Lax, the clinic is staffed with a dental hygienist, a dental assistant and two administrative assistants.

The clinic accepts both private and OHP dental insurances. Families without insurance will be asked to pay for care but may request to make payments and to be screened for a sliding scale through OHSU Financial Services.

Reimbursement for travel and lodging costs may be available through OSCSHN. For information about special funding, call 800-452-3563, x 8303.

The clinic is located on the seventh floor of Doernbecher Children's Hospital. Children needing general anesthesia will utilize the hospital for day surgery.

Children may be referred to the clinic by a physician, nurse, or parent.

For more information about the Dental Clinic, call: (503) 418-5799

1-800-452-3563, ex. 8-5799

Clinic hours: 8:30 – 4:30, Monday through Friday

Rural Health White Paper

AMCHP (Association of Maternal and Child Health Programs) has published the report, *From Rural to Remote America: Family Health Care in Alaska, Idaho, Oregon and Washington*. Both the Executive Summary and the complete report are available on the AMCHP site: <http://www.amchp.org/aboutamchp/pubs-amchp.htm#rural>.

This report on health care in rural areas was developed by the four Northwest Region X states from their individual white papers which describe the unique geography, population distribution, health data, special populations, health care delivery systems and barriers to accessing health care of each state. The purpose of the combined document is to provide a tool to better understand the factors that influence health disparities between urban and non-urban populations and to provide direction for program and policy development.

DENTAL RESOURCES

Funding

Oregon Donated Dental Services (DDS)

Oregon DDS coordinates care with volunteer dentists throughout the state who provide free comprehensive dental care to people with disabilities. The dentist is provided with support services and referrals to volunteer specialists. DDS provides funding for any necessary lab work.

- Priority is given to those with developmental disabilities .
- All ages are served.
- There are no rigid financial eligibility requirements.
- There is generally no cost to qualifying individuals; however, patients who are able may be encouraged to pay for part of their care.
- Emergency care is not provided.
- DDS provides free ORAL HYGIENE OUTREACH TRAINING on site at agency offices and group homes.

There is currently a long waiting list to receive care through DDS.

To make application or to ask about Oral Hygiene classes, contact Oregon DDS

Coordinator Joe Keenan:

PO Box 66440

Portland, OR 97290-6440

(503) 774-3898

(800) 767-6334

Oregon DDS is funded by the State of Oregon and sponsored by the Oregon Dental Association and the National Foundation of Dentistry for the Handicapped (NFDH). For additional information about Donated Dental Services, go to the NFDH web site: www.nfdh.org

In the 2003 fiscal year, 357 DDS volunteer dentists and 94 laboratories in Oregon provided \$280,881 in services to 139 people who are disabled, elderly and medically compromised.

Gul Reazee Grotto Dentistry for the Handicapped

Affiliated with the Masons, Gul Reazee assists with dental costs for children (18yrs and younger) who have diagnoses of Cerebral Palsy, Muscular Dystrophy, Myasthenia Gravis and certain levels of Mental Retardation.

**For information, call: Mr. Lloyd Fries
503-643-3843**

*the Grotto also funds equipment, lifts, computers, and assistive technology.

OSCSHN Family Support Program

Title V Family Support Funds can be used for certain dental related services. A yearly benefit of \$500.00 is available to eligible children for contribution towards orthodontia services, oral appliances, and other needs related to cleft palate and craniofacial disorders.

**For information, call: Patty Day
503-494-8704
1-800-452-3563, x8704**

Dental Access Program

Maintained through a partnership between the Multnomah County Health Department and the Healthy Communities Coalition, the Dental Access Program (DAP) serves families in the tri-county area who do not qualify for the Oregon Health Plan or Medicaid.

For information, call: (503) 988-6942

DENTAL RESOURCES

Information

Oral Health Care for People with Special Needs

Exceptional Parent Library

Guidelines for Comprehensive Care

A culmination of the multi-part series in Exceptional Parent Magazine published in 2003. It provides a comprehensive Introduction; Behavior Management Techniques; Special Diagnostic and Treatment Considerations; Professional Challenges and Responsibilities; References for further reading. Available online: eplibrary@aol.com
EP610OH \$6.95

Oral Conditions in Children with Special Needs: A Guide for Health Care Providers, available through National Oral Health Information Clearing House 1 NOHIC Way, Bethesda MD 20892
(301)402-7364
www.nohic.nidcr.nih.gov

Dental Care for Your Child With Special Needs, G. Acs & Man wai Ng, in *When Your Child Has a Disability*, edited by Mark L. Batshaw. Imprint/Baltimore: Paul H. Brookes, c2002.

National Maternal and Child **Oral Health Resource Center:**

<http://www.mchoralhealth.org>

Locating a Dentist



Your insurance company is the best source for finding a dentist qualified to work with special needs children. If you do not have an insurance carrier, the CDRC Dental Clinic may be able to help find a qualified dentist in your community. Call Kathy Vu: 503-418-5799, 1-800-452-3563, ex. 85799.

There are *Dental Finders* available by web site or phone. Some are listed below:

Oregon Dental Association 503-620-3230 1-800-452-5628 www.oregondental.org

The ODA site allows you to search for a provider in nine specialties by zip code. It also lists dental school and public health providers. On the ODA homepage, select **Find a Dentist** and enter the zip code.

American Dental Association www.ada.org

The ADA site offers a directory which can be searched by name or by city and/or zip code and specialty, but it includes only ADA members. From the main menu, select **Find a Dentist**. You can then select the state and enter search information. This site also has a link to **Local Dental Associations** which may be of assistance in your area. It also has many other useful *links*.

Oregon Board of Dentistry 503-229-5520 <http://www.oregonvos.net/~jbones/>

The Oregon Board of Dentistry has a directory of licensed professionals that can be accessed by city. From the homepage, select **Licensee Lookup** and **Licensed Dentists by City**. The list will include names and credentials (D.D.S., D.M.D.); by clicking on the name, you can determine the specialty.

CAMP



Choosing the best camp for a child to attend is a serious endeavor. Selecting a camp that will offer the greatest opportunity for the individual child and keep the child safe is critical and not always an easy task. **The National Center on Physical Activity and Disability (NCPAD)** offers a resource for parents and advocates of children with disabilities to help in selecting a camp for their child. **Discover Camp** can be found on the NCPAD website: www.ncpad.org/discover/index.html. It includes a checklist to aid in pre-camp explorations and additional information about things to consider when sending a child with a disability to camp for the first time.

The site also has personal accounts from parents: *Discovering the Potentials of Camp* by David Sommers and *Gearing up for Camp: A Primer for Parents of Children with Disabilities* by Margarita Solis, MSSA.

There are many great programs for children with special health needs, but there are also many inclusive programs to consider that do an exceptional job of including all children. An additional helpful resource is the **American Camping Association** web site: www.ACAcamps.org. The ACA annually publishes a parents' guide to accredited camps, including information on choosing a camp and a section on special needs and specialty clientele.



Other Resources

Parks and Recreation

When seeking recreational activities for your child and family, local Parks and Recreation Departments can be a resource. Contact information can usually be found in the Government listings in the phone book under City, County, Regional and State. It is helpful for you to describe your child's special needs and ask about both alternate and inclusive programs. Also, ask about scholarships; there may be funding assistance available.

Oregon State Parks

Which Oregon State Parks have ADA accessible trails, restrooms and camping? You can find this information by visiting www.oregonstateparks.org, or by calling 1-800-551-6949..

Portland Parks & Recreation

Disabled Citizens Recreation & Special Needs Accommodations www.PortlandParks.org
426 NE 12 Ave, Portland, OR 97232 503-823-4328 v/tt 503-823-4329 (fax)

Offers community-based recreation activities and leisure services specially designed for youths and adults who have a disability and/or special needs. Services are designed to assist people in developing and using their leisure time in ways that enhance their health, independence, and well-being. A program is published quarterly and can be accessed on the website or can be requested by phone.

CAMPS



A Partial List of Local Special Needs and Inclusive Camps

CAMPS	DAY or OVERNIGHT	PHONE	WEBSITES/E-MAIL/ CONTACT	POPULATION	AGES	SESSION DATES	COST
Meadowood Springs Pendleton	O	541 276-2752	www.meadowoodsprings.org	communication	ages 6-16	7/2-7/11 7/16-7/25	\$1125, sponsorships available
Camp Quality Oregon, Fall Creek Reservoir near Eugene	O	866-632-5378 503-288-8140	www.camp.qualityusa.org	cancer	ages 5 - 17	7/25-8/31	
Taloali, Stayton	O/D	503 769-6415	camptaloali@earthlink.net	deaf / hard of hearing	youth	.	\$76-\$350
Upward Bound Recreational Camp for Persons With Special Needs	O/weekends	503 897-2447	www.upwardboundcamp.org	MR/DD Physical / Christian	ages 12 thru elderly	June thru September	\$80 - \$245/ session
Westwind, Neotsu	O	503 294-7472	www.campwestwind.org westwind@ywca-pdx.org	inclusive / family camps	youth		\$201-\$350 / week
Mt. Hood Kawanis, Mt Hood	O	503 452-7416	www.hoodkiwaniscamp.org	MR/DD, physical	ages 9-35		\$535/Week
Camp Christmas Seal Program at Camp Namanu, Sandy	O	503-924-4094 Patrick Callihan	www.lungoregon.org	asthma/ inclusive	ages 8-15	weekly 7/11 - 8/28	\$325; scholarships available
Easter Seals, Vaughn, WA	O	503 228-5108	www.oreasterseals.com	LD/MR/DD/ Physical	age 9 up		
Camp Rivendale, Beaverton	D	503 642-3855	jenkinsestate@thprd.org	MR/DD/ Behavioral	ages 6-21	one week sessions 6/28 - 8/21	\$115 in district/\$172/ week out of district
Camp Ky-o-wa, Sandy	D	503 823-4328	www.PortlandParks.org	disabilities/ inclusive	ages 5-11	weekly 7/12 - 7/29	\$135 Portland residents; \$175.50 other
Oregon Zoo Camp, Portland	D	503 220-2781	www.oregonzoo.org	inclusive	ages 4-13		
Muscular Dystrophy Assoc. Portland	O	503 223-3177 503 223-9427	portlandservices@mdausa.org	muscular dystrophy	ages 6-21	7/10 - 7/17	no charge applications thru clinicians
Special Olympics Hoop Camp, Beaverton	D	503 888-5058	www.hoopcamp.net	inclusive			

Thanks to FIN Family Consultants Evelyn Lowry and Teresa Rea, and to Barbara Dworschak, for contributing to this Guide

CAMPS



Cont. from page 7

A Partial List of Local Special Needs and Inclusive Camps

CAMPS	DAY or OVERNIGHT	PHONE	WEBSITES/E-MAIL/ CONTACT	POPULATION	AGES	SESSION DATES	COST
Gales Creek Camp	O	503 968-2267	info@galescreekcamp.org	diabetes	preschool- grade 11		
Community Based Activity Prog. Adventures Without Limits, Forest Grove	D	503-968-2267 503-292-6855	www.awloutdoors.com or www.audubonportland.org	disabilities/ inclusive	ages 5-18	sessions for different ages June-August	call for details
Boy Scouts of America	D/O	503 225-5759 503 225-5754	Mark Thomas Don Cornell	boys / members of scouts inclusive	ages 7-18		
Columbia River Girl Scouts	D/O	503 620-4567	Marci Howard	girls/ inclusive	ages 7-17		
KindTree Productions Autism Rocks Retreat, Florence	O	541-521-7208	www.kindtree.org	autism	all ages + families and caregivers	8/27 - 8/29	\$75/individual plus family rates-call for details
Autistic Children's Activity Prog. Portland, Gresham, Aloha	D	503 978-3989	www.audubonportland.org	autism	ages 5 - 21	weekly 6/28 - 8/20	
ARC of Washington County	D	503 649-6110		MR/DD	5 to adult		
Camp UKANDU, Tillamook	O	1-800 577- 6552 503 795-3914	www.campukandu.org	cancer	ages 8-18 and one sibling camper	8/15 - 8/21	no charge/ applications thru oncologists
Boys and Girls Clubs / Metro	D		http://www.gclubportland.org/clubs	inclusive	age 7-18		
Camp Tapawingo, Fall City	O	503-297-7207	www.hfo.info	bleeding disorders	ages 6-15	8/1 - 8/7	\$65/ scholarships available
Camp Millennium, Douglas Co. Cancer Services, Roseburg	O	541-677-0600 Ryan Bowels	www.campmillennium.org	cancer	ages 5 - 18	7/20 - 7/27	Free
Northwest Christian Camp for the Deaf Rockaway	O	503-390-2433	www.gmdeaf.org	deaf/hard of hearing	ages 8-adult/ ages 3 and up with families	7/18 - 7/24	Call for details; scholarships available
Kinds N Cancer: Camp Agape, Camp Angelos, Sandy River	O	503-234-0468 Christine rulli	www.campangelos.org	cancer	toddler to 18 yrs and families	8/7 - 8/12	Free
Gately LD-ADD Summer Day Camp, Northeast Portland	D	503-215-2672 Susan Decker	www.gatelyyouth.org	attention deficit/ hyperactive disorder; learning disabilities	ages 9-12	six one-week sessions 6/12 - 7/30	\$250/week

Please send us your E-mail address.

We want to send the newsletter to you electronically. If you have an E-mail address that we can send it to - please E-mail Claire Tranchese at tranches@ohsu.edu.

If you do not want to receive the newsletter, please E-mail or call Claire at 503-494-4586.

Contact Information



Community Connections Network
503-494-4586



CaCoon Program
503-494-4219



Oregon Medical Home Project
503-494-3232



**FISHS: Framework for Integrating
Special Health Services**
503-494-1664

FSP - Family Support Program
503-494-8704

FIN - Family Integration Network
503-494-7657

CDRC Toll Free: 1-800-452-3563
OSCSHN Office FAX: 503-494-2755
Web: <http://cdrc.ohsu.edu/oscs hn>

Title V Newsletter
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