

LARD Meeting Minutes September 18, 2008

Participants:

Julie Aalbers	Clackamas
Judy Harvey	Jackson
David Brown	Marion
Ai-Lan Whitson	Marion
Elizabeth Binkley	Douglas
Nancy Ludwig	Lincoln
Kelli Brown	Curry
Leslie Houghton	Lane
Sarah Fife	Washington
Stephanie Kohler	Washington
Melissa Nash	Washington
Lisa Beck	Washington
Tiare Sanna	Washington
Pat Cwiklinski	Washington
Stephanie Miksa	OHSU Intern
Michaela Whistler	OHSU Intern
Heidi Suess	Multnomah
Joy McNeal	Multnomah
Elizabeth Berol-Rinder	Multnomah
Gina	State
Sara Sloan	State
Susan Greathouse	State
Cheryl Alto	State
Beth Lanham	State
Bonnie Ranno	State
Karen Bettin	State
Jazette Johnson	State
Mary Rhode	State
Vernita Reyna	State

Announcements:

- Next LARD meeting is scheduled for **Tuesday, January 27, 2009** from 1:00 to 4:00 pm. The shift to Tuesdays was requested at the state conference last May as being a better fit for most schedules. Additional LARD meeting dates for 2009 will be set after the 2009 state conference dates are confirmed.

- In 2009, LARD meeting facilitation will be shifted to Cheryl Alto. Please send future agenda items or suggestions for guest speakers or meeting topics to Cheryl. Vernita notes that it has been a pleasure acting as LARD facilitator for the past 5 years!
- For future LARD meetings, we plan to explore the possibility of video conferencing.

Providence Update:

Key Providence staff that work with WIC orders:

- Carla Patterson, Referral Intake Supervisor, 503-215-4123
- Jolene Sofish, Purchasing Supervisor, 503-215-2775
- Carrie Bauer, Access Services Manager, 503-215-7466

WIC is one customer of Providence's Home Oxygen and Medical Equipment (HME) department that provides aides for daily living to outpatients. HME's goal is to provide broader access to necessary medical supplies across the state.

HME is a special WIC vendor whose services allow for delivery of medical formulas to WIC participants when products are difficult to procure through routine channels. Procedure for requesting special medical formulas and the request forms (one fillable, one PDF) are on the WIC website.

A staffing shift occurred in July 2008 between Providence teams due to the volume of work associated with the WIC orders. The manual procedure recently became electronic to facilitate smoother processing. Two staff have primary responsibility for filling WIC orders and more staff are being trained.

Providence flow:

- Fax the request form and FI photocopies to Providence Home Medical Equipment
- Mail the current month's signed FIs
- New requests for the current month are processed immediately and shipped the next day after receipt of the order.

- If formula is not available through the warehouse or through suppliers, the order will be considered on back order and the clinic will be contacted.
- Next month's orders are received on or near the 20th of the month and are staged on the first Monday before the first business ship date (the first Monday to Friday of the month). Staging assures that there is an adequate supply of formulas to fill WIC orders.
- Formulas are shipped the first working day of the month. Providence orders do not cross months.
- If the formula is to be mailed to client, it is assumed that it is safe to deliver to the address provided. If the participant does not have an address where it is safe to leave the product at the door, a plan should be made to deliver the formula to the clinic for pick up by the client.
- Incorrect formula cannot be returned to Providence. It can be returned to the WIC clinic.

Completing the WIC order:

- Request form can be filled out and sent online or by fax.
- When completing the form manually, print clearly to enhance readability.
- Accurate WIC FI numbers are very important. It is acceptable to complete the entire first number and the last three digits of the sequential FI numbers.
- Common phone calls in the past were to clarify the need for fiber or no fiber. The forms have been updated to retrieve this information when ordering.
- Quantity area on the form should equal the total amount of formula per month being requested.
- If the product is to be mailed to the WIC clinic, please indicate clearly on the request form.
- On the request form, indicate mail to client if the product is being sent to an adult participant and mail to parent or guardian if the formula is being sent to an infant or child participant.
- When possible, wait 24 hours after faxing the order to mail FIs to allow HME time to contact the WIC clinic if there are questions regarding the request or problems filling the order.
- Send new requests as soon as they are received. For established monthly orders, send as close to the 20th of the month in order to allow processing time before the first of the next month.

- Do not send two months at the same time. If a participant is receiving a partial package for the current month and a full package for the next month, send separately.
- Mail FIs to Attention: Referral Intake

The request form was reviewed and the following suggestions were made:

1. Move the parent guardian name to the top box on the form
2. Add the type of formula (powder, concentrate or ready to use) to the information area for the prescribed formula
3. Add a line for special instructions under the mailing address
4. Add client will pick up to the instruction for Providence list

Suggested adjustments will be made to the form and posted on the website. Updated form will be for new orders only, no need to redo orders currently on file.

Cheryl Alto will work with the vendor team and Providence to periodically update their formulary as new products are become available.

Contact Providence staff if questions arise. Providence staff can work directly with clinics and usually do not work directly with clients.

Complaints or concerns regarding Providence service can be entered in TWIST with the same process used for any vendor.

Medical Formula Update:

Susan Filkins, MS RD

CDRC Feeding and Swallowing Disorders Program

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503-494-3877

WIC clients come to CDRC and refer to their WIC nutritionists with great authority as “my nutritionist”. WIC is an important partner for the feeding clinics at CDRC.

“Food first” is the best approach for good health as opposed to replacing food with supplements like Pediasure. However, formula use is vital when working with children who have special needs. If a child continues on a

formula supplement after the age of 5 years, this probably predicts their future feeding needs as feeding skills are usually in place by age 5.

Most children seen at CDRC have chronic disorders not acute conditions. Neuromuscular disorders are one example of the type of chronic disorders seen at CDRC. For these children, their muscle tone varies from not enough tone (where their muscles are too relaxed and their calorie needs are very low) to too much tone (their muscles are too tight and their calorie needs are very high).

Many children seen at CDRC present with sensory feeding difficulties due to autism or prematurity. They have difficulty with their bodies in the world and do not approach feeding efficiently. Medical diagnoses are diverse and often clustered. These patients frequently resist advancing textures and are extremely selective.

Failure to thrive (FTT) is a description of how an individual is growing but not the underlying disorder. The presenting problems are varied but poor weight gain is common as children are not moving well through developmental milestones.

Feeding team members are involved in evaluation. Feeding skills match the rest of a child's development. Evaluation will include nutrition assessment, developmental assessment, a sensory profile, a psychosocial assessment and a check for oral anomalies. OT, ST, MSW and RD are on the hospital based feeding team with MDs and PNPs.

Feeding teams are located in Portland, Eugene and Medford through OHSU, Providence and Emmanuel. In addition, 20 Educational Service District (ESD) throughout Oregon have feeding teams however, RDs are not associated with these teams. CDRC sees children ages birth to 21 years. Peak age of referrals is at birth and 9 to 18 months old.

Nutrition assessment includes looking at problems associated with intake, digestion, absorption and altered nutrient requirements. Awareness of drug nutrient interactions, growth velocity and nutrient adequacy is necessary.

Nutrition assessment with children who are diagnosed with syndromes is challenging. Is the poor growth due to the syndrome itself or to the poor feeding due to the feeding difficulties associated with the syndrome?

When an infant demonstrates **normal development**, they will be ready for strained foods at 4 to 6 months and for more advanced textures at 7 to 9 months. There are windows of opportunity where it is time to progress textures for all infants, breastfed and formula fed. Breastfed babies are more flavored exposed and often don't like baby foods so they miss the developmental window toward advancing textures. Growth begins to fall off as appetite diminishes and feeding skills are delayed. We need to do a better job of **anticipatory guidance** at 4 to 6 months when signs of readiness occur such as trunk stability, the ability to lean in and pull away and communication skills become more apparent.

Frequently used formulas at CDRC include Nutren Junior, Resource for Kids 1.5, Peptamen Junior, Pediasure and other specialty infant formulas (preterm and hypoallergenic). Hopefully, as a child decreases their formula intake, their food intake increases. With oral motor feeding difficulties, complementary foods are not taken successfully resulting in limited amounts eaten so formula intake can assure nutrient adequacy for these children.

Formula manufacturers are in a state of transition at this time with mergers, recalls and enhancements such as probiotics etc. It can be challenging to keep abreast of all developments.

Pediasure is a basic pediatric formula. At age 12 months, a child should be able to drink from a cup and chew chopped foods. Children who can't accomplish this safely need formula even if growth is adequate. They need nutrients from infant or pediatric formula. Infant formula is rarely used after one year of age. A standard pediatric formula should be used to when children don't have developmental readiness for food or to support growth when they are FTT. If a child is on target, provide family support for mealtime management and formulas will be a short term option and the child will return to milk later.

Resource for Kids 1.5 is being used to compensate for those children where volume issues are a concern or a higher than typical energy requirement is present. Extra fat and carbohydrate can make reflux worse when present. **High calorie formulas** are essential for in home use when a 24 hour feeding schedule like in a hospital is not realistic. Regular formula can be delivered in 9 feedings per 24 hours using a pump for overnight feedings however; this can be disruptive to sleep patterns. A high calorie formula, like 1.5, allows the same calorie intake in 6 feedings. Establishing a schedule that works is very important to families. High calorie formulas can't also be a help when

families don't follow through with provision of meals and snacks as recommended.

Compleat Pediatric is used for tube-feeding as is helpful with managing reflux and preventing dumping syndrome. Some families include this product when making their own tube-feedings. 100% free amino acid products are rarely used except with situations where true and severe food allergies are present.

Peptamen Junior is not used frequently but helps with malabsorption issues and is usually tube fed.

Splash is gluten free, casein free beverage that is packaged in a juice box. This gives another option for families who want their child to be out in the world with a product that helps them fit in. Splash can help to assure nutrient adequacy if variety of food intake is limited.

Communication between CDRC and WIC clinics could be enhanced. CDRC RDs could have their name on prescriptions to facilitate contact. Families can sign release of information to have feeding clinic notes sent to the WIC clinic. Information such as whether a condition is chronic or acute, what the intervention plan is and when they will be seen again at CDRC would be helpful so WIC can support the family. Avoid putting names in emails due to confidentiality but date of birth and first name with last initial should work when communicating with WIC.

Collaboration is good as we work together for the health of families that are served by both WIC and CDRC.

Medical Documentation for the New Food Packages:

Cheryl Alto, MS RD

A group of WIC RDs participated in three conference calls to develop draft forms to use for Medical Documentation as required by the federal regulations for new food packages. Thank you to staff from Douglas, Marion, Lane, Jackson, Washington, Deschutes, Clackamas, Baker and Salud for sharing their insights and expertise on this advisory group! Input has also been received from Dr. Beth Epstein and state nutrition consultants.

Changes requiring prescriptions:

- Food can be allowed in addition to medical formulas
- Children need prescriptions for soy milk (although women do not). Soy milk prescriptions are required to advise participant's medical provider of the potential for nutrient deficiencies.
- Children over age 2 years and women need prescription for whole milk

Timeline:

- Phase 1: development by end of 2008
- Phase 2: staff training during spring of 2009
- Phase 3: provider and partner education during summer of 2009
- Implementation: August 2009

The advisory group started working on adapting medical documentation forms from WIC Works. Suggestions include having one form for each category on tear pads that are color coded. Electronic versions should be available in a fillable form and be available for downloading. All forms need to be accessible for providers.

Recent feedback from both local agencies and partners indicates a strong interest in having one universal medical documentation form. The work group will have a conference call in November to discuss the feasibility of one form.

New prescription components in interim rules:

Date of prescription

Contact information for health care provider

Amount of formula needed

Prescribed amounts of food

Reviewed forms and cover letter for providers. Suggestions include:

- Remove amount per day for milk and soy beverage if not specifically required by new regulations
- Eliminate the milk substitution form that is under consideration as fewer forms is better
- Change verbiage from "low fat" to "1%, 2% or nonfat"
- Add place for special instruction or notes
- Change "breakfast cereal" to "cereal"
- Indicate that the default is a full formula or food package

- Add “reason beyond family preference” for whole milk since parental preference is not qualifying factor
- Simplify form. It is too busy to be easy to use.
- Work toward minimum documentation as it currently looks overwhelming
- Allow for flexibility for RD to fill out and send to doctor or for doctors to complete
- Change “health care provider” to MD, DO, etc to clearly identify those who have prescriptive authority in Oregon
- Ad lib is maximum or amount per day (use calorie need to determine amount)
- Rework title to make it clearer
- Be sure order of foods is the same on all forms
- Add “otherwise” to “unless indicated”
- Remove powder products for children and women as these are not needed.
- Reduce confusion by consolidating forms
- Allow fiber and non-fiber products to be mixed on prescription
- Remove ad lib as it is a confusing concept on a prescription. Specific amounts are needed
- Remember that any changes on prescriptions need provider’s approval.
- Communicating how to fill out forms could be challenging. Medical community needs to give feedback. Work with providers to reduce potential resentment for this burdensome process.

Next steps:

- Work group conference call 1st Tuesday of November.
- More discussion at January LARD meeting.
- Continue to give Cheryl feedback throughout this process ...your input is appreciated!