

Child and Family Instructional Information

Constipation and Stool Continence; Neurogenic Bowel

There are many problems that can cause nerve damage to the lower spine including spina bifida, tethered spinal cord, imperforate anus, spine tumors (or other spinal lesions), spinal injury (motor vehicle accident, falls, etc.). If your child has one of these problems then there is a good chance your child is constipated or is at risk of becoming constipated. Your child may also have difficulty becoming continent of stool (potty-trained for stool) when stool continence is appropriate for age.

Please note: Constipation in the neurologically challenged child is different from constipation in the otherwise healthy child (see separate handout).

In order to understand constipation and continence of the neurogenic bowel, one must first understand normal bowel function.

Physiology of Normal Bowel Function:

Stool is formed as a result of digestion of the food eaten. The digestive process begins when anything is taken into the mouth. Saliva starts to breakdown the food in the mouth. As it passes down the esophagus and into the stomach, further breakdown occurs. It then passes into the small intestines in a semi-liquid form. The body begins to absorb nutrients through the small intestine wall, leaving behind waste products. This liquid is moved through the small intestine by peristalsis.

Peristalsis is a reflex caused by a distention of the intestine from the liquid food, followed by a constriction in the same area of distention. This propels the food forward. As peristalsis moves the liquid toward the large intestine all of the nutrients are absorbed. The liquid entering the large intestine is liquid waste.

The large intestine or colon is in the shape of an upside down “U”. The motility slows down allowing for water to be reabsorbed and soft stool to be formed. The colon deposits the stool into the rectum. The rectum can be considered a “holding area” very similar to the bladder’s role for urine. It is empty and fills with stool prior to having a bowel movement.

The internal anal sphincter is at the end of the rectum. It is an involuntarily controlled muscle that automatically opens when the rectum is full of stool. This allows the stool to move into the anal canal. This passage also activates a signal that goes to the spinal cord and up to the brain alerting the individual that a bowel movement is imminent.

The external anal sphincter is a voluntarily controlled muscle at the other end of the anal canal. When the brain receives the impending bowel movement signal, a message is sent to the external anal sphincter to contract. It remains closed until the individual signals it is safe to relax. The stool passes out of the body to the toilet.

Most people find they have a routine time for a bowel movement. For many it is in the morning after a hot beverage, for some it is in the evening after a warm bath or shower. Some people also will note that a bowel movement does not happen everyday but every other day.

Children with nerve problems to their lower spine will have abnormal bowel function, which is referred to as “neurogenic bowel” (not unlike the “neurogenic bladder”). In the next section we will discuss the physiology of the neurogenic bowel.

Physiology of the Neurogenic Bowel

The neurogenic bowel is a bowel that has a lack of nerve innervation due to interruption in the spinal cord. The interruption to the spinal cord will most often be caused by spina bifida but may be caused by spinal cord lesions (tumor), tethered spinal cords or accidents (motor vehicle). The nerves on the spinal cord that control the bowel function are at the S2-S5 level (nerves that control the feet are above the S2 level). The majority of children with spina bifida have lesions that

occur at or above the S2 level. Essentially every person with spina bifida will have some degree of bowel dysfunction.

The major problems of the neurogenic bowel are constipation and stool incontinence. Children with neurogenic bowels may develop constipation and stool incontinence for the following reasons:

- Lack of awareness that the rectum is filled with stool.
- Slow motility due to the poor nerve innervations from the spine. In other words, the bowel does not have normal peristalsis. This allows for stool to ‘sit’ longer in the colon.
- Inability to effectively empty their bowel completely.

How does the abnormal physiology cause constipation and subsequent stool incontinence?

Due to the slow motility and inability to completely empty the bowel, the stool “sits” longer in the bowel. As stool “sits” longer in the bowel more water is reabsorbed from the stool. When too much water is reabsorbed from the stool, the stool becomes hard. The hard stool is more difficult to move through the bowel to be eliminated. Hard stool then accumulates in the bowel, stretching (distending) the wall of the bowel. As more and more stool accumulates the colon becomes so distended that the peristalsis further fails. Often, so much hard stool accumulates that the stool bolus becomes impacted (stuck). The individual continues to eat and more stool continues to be formed but stops behind the “stuck stool”. As the build up of stool continues, the pressure is great and forces the stool that is still liquid around the “stuck stool” without dislodging it. The liquid stool is expelled as diarrhea. This is frequently called a “blow out”. Unfortunately the pressure is relieved, but the hard stool remains. If this is not cleared out, these blowouts will continue.

Also, your child will have a lack of awareness that the bowel is full. This is due to an inability of the spinal cord to transmit the message to the brain. The brain does not respond and send a signal to the

external anal sphincter to remain closed. Therefore, the child never knows a bowel movement is about to occur. This results in a bowel accident.

Other concerns:

- Decreased muscle tone: As the above cycle continues there is increased stretching of the bowel, so that there is very little muscle tone. This results in further poor motility.
- Bladder problems: The bowel full of stool can take up so much space in the abdomen that the bladder cannot fill or empty completely. This can lead to urinary incontinence and urinary tract infections.
- Medications: Medications that are commonly used to treat the bladder and other associated problems also can cause constipation such as; ditropan, tofranil detrol, levsin, heart medications, medications for high blood pressure, pain medication and anesthesia. Please note, while often brought up as a concern, there is actually no evidence that constipation causes or contributes to colon cancer.

How do I know if my child is constipated?

Your child may be constipated if your child :

- Has stool that is hard (small hard balls)
- Has intermittent diarrhea
- Is past the age of normal potty training and is incontinent of stool
- Has bowel movements every 3 days or more

Based on the history and physical exam, your practitioner may simply just assume your child is constipated (based on diagnosis, symptoms and physical exam) and treat your child for constipation. If the history and physical exam are too difficult to illicit, or “unknown”, then the

practitioner may want to obtain an x-ray to thoroughly assess for constipation. The x-ray is useful as it allows the doctor/nurse practitioner to assess exactly how constipated a child is and then tailor treatment. However, the x-ray does expose the children to a bit of radiation so, if there is a high suspicion of constipation it may be better to just go ahead and treat the child without the x-ray.

What are the goals of neurogenic bowel management?

Goals will vary depending on the age of your child, goals of the child and family, and degree and chronicity of constipation.

Infants and Toddlers (pre-potty training age)

To prevent stool incontinence at a later date we must prevent problems before they occur. Many clinics/practitioners do not address bowel programs in this age group because it is “age-appropriate” to wear diapers. It has been our experience that constipation is a big problem and may be the actual cause of difficulty in achieving stool continence later in life. Children who have never experienced long periods of constipation achieve continence with fewer problems than children who have been constipated. That is why, in our program, bowel management begins in infancy.

There is nothing we can do, at this time, to “cure” the nerve damage already done, but we can prevent your child from becoming constipated and impacted with hard stool. If we begin potty training for stool at the “typical” age and we are able to begin with a “normal” size, not impacted, colon, then not only are our chances for a successful bowel program higher, but the program will be much easier and work quicker.

The goal of a bowel program for an infant is to maintain a normal stool consistency (soft, not formed, easy to push) and assure that the younger infant has bowel movements several times per day. Most infants, especially if breast-fed, will have normal stools in the first few months of life. Constipation tends to present at the introduction of solid foods. Constant smearing of stool on the diaper as well as hard ball-shaped stool may be among the first signs of constipation.

The infant's pediatrician, spina bifida nurse, or urology practitioner can be contacted for advice if constipation is present.

Older Child (post-potty-training age)

The goal of the bowel program in the older child is to “wear underwear”. It is important to realize that the bowel continence program in the neurogenically challenged child is VERY DIFFICULT and may take up to 6 months to establish. Length of treatment (length of time from start of treatment until your child is free of constipation and continent of stool) will depend greatly on how long your child has been constipated. It is imperative that both the child and the parents want to start the bowel program and are willing to commit to it. If the family or child is not ready for the commitment then every effort should be made to at least keep the child free from constipation until the child and family are ready for a continence program.

What are the treatments for my child's neurogenic bowel?

Diet and Fluids

A diet that contains plenty of fiber and fluids can help prevent constipation.

- Fiber

Fiber is the portion of plant foods that our bodies cannot digest. Fiber prevents constipation by absorbing water and enlarging the stool. This makes it easier for the stool to be pushed out. This is also called giving bulk to the stool. Try to include fiber in every meal.

Increase fiber gradually. Adding too much fiber too quickly can cause cramping, diarrhea and discomfort. The gradual addition of fiber to the diet will allow the bowel time to adjust.

Our nutrition and dietetics department here at UCSF recommends the age of the child plus 2 grams of fiber as a goal for fiber intake in children (example: a 6 year old child plus 2 grams of fiber would be 8 grams of fiber per day).

Fiber by diet:

- Increase daily intake of raw vegetables and fruits. Avoid too many apples or bananas because this may worsen constipation. Dried apricots (excellent source of fiber) or other dried fruits are often popular with kids because they taste sweet.
- Limit dairy products like milk, cheese, yogurt, etc. The child should not exceed their daily allowance for dairy products to stimulate growth.
- Encourage fruit juices like prune, grape or other juices with pulp.
- May need to try fiber cookies or other cookies or snack bars containing high fiber content.
- Try cereals high in fiber or containing bran products.
- There are 2 grams of fiber in; 1 1/2 grapefruits, 3 cups of watermelon, 20 cherries, 1/2 cup broccoli, 3/4 cup cauliflower

Fiber by supplement:

There are many different types of supplemental fiber and they are all over the counter. For the younger children, the powder form might be the best choice as it can easily be mixed in liquid. For the older child, who can swallow pills, the tablet or capsule form is probably the easiest. For the child somewhere “inbetween”, perhaps the wafers would be the best choice (in our practice, we call the fiber wafers “Scooby Snacks”).

Remember, the fluid/fiber ratio is important! Not enough fluid with the fiber can make constipation worse. If using the wafers or tablets, it is best to have the child drink the liquid first and then give them the fiber (that way if they don't drink all the liquid you can give them less fiber). Of the powders, benefiber, seems to dissolve the best in water/juice and; therefore, more palatable to small children. Benefiber is available over the counter at any local pharmacy or

may be ordered directly through from the company that produces it. You may call (800) 828-9194 to order it.

Because your child has a neurogenic bowel, your insurance may cover fiber, despite it being “over the counter”. If you have CCS, then CCS will cover the fiber.

- **Fluids**

Drink lots of water and other fluids. Fiber absorbs large amounts of water in the intestine. A high fiber diet can actually cause constipation if plenty of fluids are not taken. Four to six eight ounce glasses of water or other liquid a day will prevent problems with the fiber.

Exercise

Regular activity helps prevent constipation by stimulating the peristaltic motility. It is important to encourage the young person to continue a daily exercise program, which may include wheel chair activities such as push-ups and transfers. A physical therapist can help develop an exercise program. Also the physical therapist or social worker can provide information regarding community agencies that provide recreational activities for individuals with a physical disability such as; wheelchair racing, basketball, dancing, tennis, skiing.

How do I start a bowel continence program for my child?

Ideally bowel management has begun at birth and the child has achieved continence by school entry. However, in reality, such factors as hospitalizations, illness, lack of motivation, as well as various socioeconomic factors have been barriers to achieving continence. Bowel management can be very challenging.

Note: treatment may take several months and in severe cases a year. Successful treatment is dependent upon having patience and not stopping the therapy too early.

Our recommended treatment will be in three parts:

1) Clean Out

The goal of the “Clean Out” is to literally clean out the entire bowel of stool. Depending on the amount of constipation (or retained stool) this may take 3 to 7 days at home or 1-2 days in the hospital.

2) Maintenance Phase

The goal of the “Maintenance Phase” is to maintain the empty bowel by having 1-2 soft stools everyday. This phase will always involve medication initially. The maintenance medication is weaned over 6 months to a year and, in a few children, eventually discontinued.

3) Daily sit

The goal of the “Daily Sit” is to make the daily bowel movements “continent” bowel movements. In other words, have a predictable bowel movement at the same time every day. If your child is appropriately “clean out” and your child has a normal sized stool at the same time every day then your child will not have an accident at another less predictable time of day. Of course, this is easier said than done.

Medications:

The 3 different phases will require 3 different types of medications. There are many different types of medicines used in the treatment of constipation. All have their own risks and benefits. The 4 primary categories are:

- Lubricants (mineral oil)
- Stimulants – senna (senokot), bisacodyl (ducolax)
- Stool Softeners - ducosate (colace)
- Osmotic Laxatives – polyethylene glycol (Miralax, GO-Lytely), magnesium supplements (magnesium citrate, milk of magnesia), lactulose (enulose)

In our practice, for the treatment of chronic constipation, we use primarily the lubricants and the osmotic laxatives. This is because the lubricants and osmotic laxatives are safe, effective and are the least likely to be absorbed into the body (with the exception of the magnesium

supplements which we only use for the clean out phase).

The stimulants are best used only for the short term; for example, cleaning the bowel prior to a procedure. Some believe that chronic use of stimulants will take away the body's normal reflex to have a bowel movement (in other words stimulants can become addictive). The stool softeners, such as colace, are best used to treat constipation in patients who need to avoid straining (for example after surgery).

The primary side effects of all stool medications include; soiling, gas, nausea, vomiting, abdominal pain and diarrhea.

Phase 1 - Clean Out:

The clean out process is carried out over the first three days to a week. It is essential to get out all the stool initially. The success of the entire treatment is dependent on a successful initial clean out. Stool continence cannot be achieved without this initial process. We have found that older children and almost all adolescents (who quite possibly have been constipated their entire life) are most effectively treated by hospital admission for an aggressive "clean out". The medicines used in the hospital are essentially stronger and work better, but intravenous (IV) hydration is required. Also, in the hospital, we can place a small tube (the size of a piece of spaghetti noodle) through your child's nose and into the stomach. Then, the medication can be placed through the tube and the child does not have to "drink" the medicine. Younger children have difficulty "drinking" the large amounts of medicine that are required for a clean out. The other benefit of the hospitalized "clean out" is it can be done in less time, usually 1-2 days. Whether in the hospital or at home, the clean out phase can only be done successfully with medication. The following medications may be used:

- **Polyethylene glycol**

Polyethylene glycol is an osmotic laxative. GoLYTELY is the form most often used in the hospital for children who are severely constipated or prior to bowel surgery to completely cleanout the bowel. Miralax is a milder version can be taken at home. It moves the stool through the bowel using an electrolyte solution to cause osmotic

pressure. This is our first choice for the clean out phase due to its tolerability to children (doesn't taste so bad), is effective, and has limited side effects. In fact, in our clinical experience, polyethylene glycol causes the least amount of side effects (nausea, cramping, soiling and bloating) of all the "clean out" medications. The primary negatives of polyethylene glycol are that it requires a prescription, is not covered by all insurances and can be expensive.

- **Mineral Oil**

Mineral oil is a lubricant. The oil lubricates the bowel allowing the stool to pass easier and preventing the body from reabsorbing too much water from the stool (keeping it soft). The benefit of mineral oil is it is inexpensive and over the counter, therefore, easy to obtain. Children do not seem to suffer significant cramping symptoms. One problem with mineral oil is some children refuse to take it due to the taste and consistency. However, mineral oil can be made quite palatable by mixing with ice and fruit in a blender or mixing with ice cream in a blender. Another problem with mineral oil, but only as a clean out, is it will tend to "ooze" from the rectum long after the clean out causing difficulty attaining continence.

- **Magnesium supplements (Magnesium Citrate, Milk of Magnesia)**

Magnesium supplement is another osmotic laxative. While it is easy to obtain (over the counter), inexpensive and quite effective, it does seem to cause the most significant cramping of the 3 medications.

Phase 2 - Maintenance:

Now that the bowel has been "cleaned out" we must keep the bowel cleaned out. We do this in the maintenance phase. The maintenance phase is ongoing and life-long. Changes will often need to be made in the maintenance phase. This process allows for maintenance of regular bowel movements and keeping the bowel empty.

Medications:

- **Polyethylene glycol**

Polyethylene glycol can be used as a maintenance medication (in smaller doses) in addition to being used as a clean out medication. It helps to ensure that a child is having 1-2 soft stools per day. As the bowel regains its elasticity and form, over time, the dose can be gradually decreased. Most children will require the Miralax (in varying doses) for the first 6 months to years of the maintenance program.

- **Mineral Oil**

Mineral oil can also be used effectively as a maintenance medication, and with the smaller doses used in the maintenance phase, does not seem to cause soiling or oozing of stool that occurs when using mineral oil as a clean out. There is some concern, in that, if mineral oil is taken with meals for long period of time (more than 6 months) there is some decreased absorption of the fat-soluble vitamins. Therefore, it is important to take the mineral oil at a time other than mealtime.

- **Lactulose**

Lactulose is a maintenance medication used for chronic constipation. The dose needs to be slowly titrated up; however, until the desired effect is reached (1 to 2 soft stools per day). Starting on “too high” of a dose increases the symptoms of cramping and gas. This medication is prescription only. In infants we have the most experience with lactulose.

Phase 3 - Daily sit:

If your family and child is motivated and your child is of normal potty training age, then the daily sit is a crucial component of the bowel program for the neurogenically challenged child. The goal is to have the child have a bowel movement at a socially acceptable time, in a socially acceptable place every day. This is done by sitting on the toilet for 15-20 minutes after a meal.

Depending on the severity of constipation the initial daily sit will vary.

In most patients, especially if the child started out constipated, the daily sit will be preceded by an enema in and less severe cases a suppository. We want your child to have a normal size stool at a PREDICTABLE time of day. The goal here is to “make an offer the bowel can not refuse” at a specific time.

Timing of the Daily Sit

Careful consideration must be given to the timing of the daily sit. It must be done at the same time every day and it should be done after a meal. It is important to have the child sit after a meal because there is a normal reflex (gastro-colic reflex) that stimulates the bowel to move. Sitting on the toilet after a meal takes advantage of this reflex. Usually families will perform the daily sit after dinner and/or breakfast. Especially in the beginning, this can be very time consuming, as long as 30-60 minutes per day, so you must choose a mealtime after which you have time. Some families have more time in the afternoon and therefore will do the bowel program after an afternoon snack.

Some clinicians and many articles recommend that children sit on the toilet after EVERY meal. However, in our practice we find that to be VERY difficult, especially with the school age child. So, depending on your child's individual situation and severity, you will be asked to have your child sit on the toilet after breakfast, dinner or both.

Enema's

So after the bowel has been cleaned out you will most likely start with enemas prior to sitting on the toilet. Unless your child was not constipated to begin with in which case a suppository may be adequate. The enema is used to stimulate the rectum and bowel to expel stool. There are many different kinds of enemas, we will most often use fleets enemas.

When giving an enema:

1. Positioning can be difficult depending on your child's level of function. The best is to place on all fours or on the left side in the knee/chest position. You can use a pillow to prop under the

- abdomen so that the bottom is higher than the bowel and head. Some older children can lay over the edge of the bathtub with a rolled towel on the edge for greater comfort. Younger children can lie across their parents lap.
2. Follow the directions on the package.
 3. Position the child so the enema solution will be retained for about 10 minutes.
 1. After ten minutes, have the child sit on the toilet or potty chair.

Toilet Sitting Position:

- • The child's feet should be supported by the floor or a stepping stool to assist in
- pushing and emptying the bowel.
- • Knees higher than buttocks (again use foot stool if necessary)
- • Teach child to "bear down" by coughing, blowing bubbles, laughing or grunting
- • Have the child look in toilet to see how much stool has been eliminated prior to
- flushing. A preschool child should eliminate 6-8 inches of stool per day.
- • After child has a bowel movement, praise the child
- • Child should not sit longer than 15-20 minutes.
- • If no bowel movement after 15-20 minutes the child should get up

Suppositories:

If the child is starting this program "not constipated" then suppositories will be sufficient. Suppositories are also used after enemas have been successful in producing bowel movements at the desired time. The children can then graduate to suppositories. A suppository is a small waxy bullet shaped object that melts from body heat once inserted into the rectum. Inserting the suppository helps to stimulate the nerves of the rectum to push the stool out. We will usually use a ducolax or glycerin suppository. We will usually start with ducolax as it actually stimulates the bowel, however, after success with the ducolax suppository we will again "graduate" to the glycerin suppository, which really just lubricates the rectum.

When using suppositories please note the following:

- 1) The bowel must be cleanout or it will not work. Also the maintenance program must be well enough established that the child is having daily soft stools that are formed.
- 2) The timing must be at the same time every day and after a meal
- 3) Lie on the left side
- 4) Insert suppository tapered end first 1 1/2 to 2 inches into the rectum. Make sure the suppository is not inserted into stool. If stool is in the rectum first have the child try to push it out, if unsuccessful, manually remove it with your finger. You should feel it pass through the internal anal sphincter. In order to keep suppository in place you may need to hold the buttocks together.
- 5) The child should lie quietly for 10-15 minutes. This allows suppository to melt and begin to work.
- 6) Have the child sit on the toilet or potty chair for 15-20 minutes. (See toilet sitting position above)

What if my child is starting a continence program free of constipation?

If your child has been free of constipation throughout infancy (and currently) then you may skip the “clean out” as your child is already on a maintenance program. All that is left is the “daily sit”. Your child is free of constipation, so now our only goal is to assist your child in having his/her bowel movement at a predictable time of day. Although we expect the children whom have always been free of constipation to progress quicker than constipated children with their bowel programs, it can still be quite a challenge.

The first step is to acknowledge if there is a “typical” time of day that your child will have a bowel movement. If this is known, then it is best to start the “daily sit” at this time. Once the child is having regular bowel movements in the potty by using the suppository, you may elect to try decreasing the frequency of suppository, but continue to sit on the potty at the same time everyday.

Is there anything else I can do to help my child solve this problem?

Yes!

- Avoid blame, criticism or punishment for bowel accidents.
- Always reward your child for following the recommendations (not necessarily for success). Most literature will ask you to reward your child for a successful continent bowel movement. In our opinion, the child does not yet know how to do this, so we would be essentially setting them up for failure. We prefer to reward children for following our recommendations and taking responsibility. For example, sitting without complaining for the entire 15 minutes, cooperating with medications, helping to keep track of bowel movements and accidents, etc.
- Do not allow siblings or classmates to tease the child.
- Encourage the child's teacher to participate in this process, if necessary. We can write a note for you if needed for the school.

What about biofeedback?

Biofeedback has become quite popular in the treatment of stool and urinary incontinence; however, at this point in time there is only limited evidence showing a short-term benefit.

It appears that there is not long-term benefit from adding biofeedback training to conventional treatment of constipation in children.

Individual Bowel Program Worksheet
(next page)

Individual Bowel Program Worksheet

Clean out:

- Admit** to hospital for clean out with GoLYTELY
 - Miralax**
 - 1 scoop in 8 oz of liquid 3 times per day for _____ days
 - 1/2 of a scoop in 4 oz of liquid 3 times per day for _____ days
 - Mineral oil**
 - _____ oz _____ times per day for _____ days
 - Magnesium citrate (Mg Citrate)**
 - 1/2 bottle (150 ml's) at bedtime for _____ nights
 - 1 bottle (300 ml's) at bedtime for _____ nights
 - Other** _____
-

Maintenance:

- Medication**
 - Miralax**
 - 1 scoop in 8 oz
 - 1/2 scoop in 4 oz liquid
 - _____ teaspoons in _____ oz liquid
 - Other _____
 - Every night every morning every afternoon
 - Only if no bowel movement that day
 - Lactulose**
 - _____ teaspoon(s)
 - _____ tablespoon(s)
 - 2 times per day 3 times per day
 - Other** _____
- Fiber**
 - Wafers Tablet/ Capsule Powder
 - 1/2 the recommended adult dose with 4 oz of liquid
 - 1 full recommended adult dose with 8 oz liquid
 - _____ teaspoons with _____ ounces of liquid
 - Every morning every night
- Daily Sit** (*see handout for enema and suppository administration instruction*)
 - Fleet's enema
 - Pediatric
 - Adult
 - Suppository
 - Glycerin
 - Ducolax
 - Have your child sit on the toilet for 15 to 20
 - After dinner after lunch after breakfast after snack at _____
 - Document all continent stools that occur at desired time and document all accidents and bring log with you to your next appointment.

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See the next page for contact information.

Contact Information:

Laurence S. Baskin, MD

lbaskin@urology.ucsf.edu

Hillary Copp, MD, MS

<http://www.urology.ucsf.edu/faculty/contact?fid=505>

Michael DiSandro, MD

<http://www.urology.ucsf.edu/faculty/contact?fid=509>

Appointments & Location

UCSF Medical Center, Parnassus Campus

400 Parnassus Avenue, Suite A-610

San Francisco, CA 94143-0330

Phone 415/353-2200

Fax 415/353-2480

Children's Hospital & Research Center Oakland

747 52nd Street Ambulatory Care 4th

Oakland, CA 94609

Phone 510/428-3402

PEDIATRIC NURSE PRACTITIONERS

Anne Arnhym, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415/443-0541

anne.arnhym@ucsfmedctr.org

Angelique Champeau, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415/443-5632

Angelique.Champeau@ucsfmedctr.org

Christine Kennedy, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415-443-0703

KennedyCE@urology.ucsf.edu