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Most people in the developmental disabilities field know about Fragile X Syndrome. We know that it is the most common cause of intellectual disability and that it can be fairly mild in effect or it can cause more severe impairment to cognitive or intellectual abilities. Fragile X Syndrome (FXS) is also the most common known cause of autism and can also include symptoms such as delays in language or in development of speech. What many people, even in the DD field do not know...is that Fragile X is an inherited disorder that can cause medical problems for family members who are carriers of the FX gene but do not have the actual disorder.

What's more important is that these associated problems often do not get diagnosed correctly unless the person is tested for the FX gene to either rule this out as a cause or identify it as a precursor. If you have an immediate family member with Fragile X Syndrome, you should be tested for it also.

If you have a child with Fragile X Syndrome, you either have the disorder or you are a carrier of the gene. If you are a carrier, you may not have any symptoms at all that can be related to FXS. Or....you may have different symptoms such as early menopause or dementia-like symptoms. Since the X chromosome is found in both males and females, both parents can be carriers (men have XY sex chromosomes, women have XX). This is called an X-linked genetic disorder because it is carried on the X chromosome. The X chromosome undergoes a mutation where parts of the chromosome 'repeat' themselves multiple times, causing the Fragile X Syndrome and can cause symptoms in carriers of the gene.

Fragile X-associated Tremor/Ataxia Syndrome (also known as FXTAS) is one of the conditions that a carrier could experience. It is easily misdiagnosed as dementia or Parkinson's Disease as you can see from this list of potential symptoms:

*Ataxia (unsteadiness) when walking, can cause frequent falls

- Tremors—often called “intention” tremors because the shaking often occurs or gets worse when the person “intends” to do something, like picking up something or pouring a glass of water
- Memory problems—short term memory especially
- Numbness in hands and feet
- Begins between ages 50-80

If you know someone with these symptoms and they could be a carrier of FXS, get tested!

Primary Ovarian Insufficiency (POI or FXPOI) is an FX carrier-associated condition also. As with the previous condition, there could be other causes for POI which can negate getting a correct diagnosis in individuals who are FX carriers. In FXPOI, the woman goes through menopause before age 40 and may also have ovarian dysfunction such as decreased fertility (difficulty or inability to get pregnant).

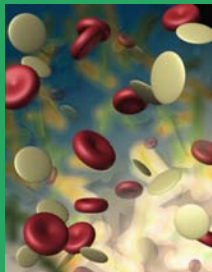
It is possible for multi-generations to experience the effects of Fragile X Syndrome in different ways. Getting a blood test to check for the FX gene is the first step to correct diagnosis. It is suggested that the following people be tested:

1. Any child with a developmental delay in speech, language, or motor function.
2. Any child with a diagnosis of learning disability, autism, or autistic spectrum disorder.
3. Anyone with a family history of FX.
4. Women who are carriers and pregnant or who have early menopause or POI.
5. Anyone over 50 with tremors and symptoms listed above.

For more information on Fragile X go to: <http://www.fragilex.org>.

Fragile X Syndrome: Pass It On

Blood Thinners Compete



With heart disease and stroke both on the World Health Organization's TOP 10 list of most common killers, it is no wonder why the TOP 2 drugs for sales in the world are Plavix and Lipitor. Plavix is Bristol-Myers' blood thinning drug and Lipitor is the money-making cholesterol treatment made by Pfizer. It has been about 6 years that Plavix has dominated the market for blood thinning medications. That may be about to end.

Just this month, Eli Lilly & Company got the nod to sell its new medication called Effient for treatment of blood clots (the major player in both heart disease and strokes). Lilly's Effient will be a challenger to Plavix as the standard of care for patients having surgery for blocked arteries in the heart.

Effient (prasugrel) may be more effective than Plavix but it also has more risks connected to its use. Effient gets to a therapeutic level in the blood faster meaning it is thinning the blood more quickly...a good thing. But, it also increases bleeding risks more than Plavix. Recently, according to industry publications, the FDA has been concerned about the effectiveness of Plavix and has requested additional stud-

ies related to its use. They are evaluating studies that reported that Plavix may not work in some patients with certain genetic mutations or that the effects could be altered by the patient also taking proton pump inhibitors, which are drugs commonly taken for acid reflux. Since our consumers fall into both of the above categories...and in large amounts (many have GERD and genetic mutations)...this bears watching for our consumers who may be on Plavix.

The role of aspirin and Coumadin in the prevention of stroke and heart attack had been the tried and true medications for many people for many years, until Plavix. The recommended aspirin dose is 81 mg per day for preventive anticoagulation. In studies, the lower dose up to 150 mg showed no difference in effect than higher doses of aspirin which increase a person's chances of GI bleeding. So, stick with the lower 81 mg dose. The Journal of American College of Cardiology has an interesting article about aspirin's use. *The Role of Aspirin in Cardiac Prevention* can be found at:

<http://www.medscape.com/view>

New Med News: A Gel for Urinary Incontinence

Gelnique™ by Watson



The FDA has approved Gelnique™ (oxybutynin chloride), a new product that will be available by prescription in March or April 2009. It is the very first topical gel used to treat overactive bladder (OAB) with symptoms of urge urinary incontinence, urgency, and frequency. We do have many consumers with these symptoms, so this may make Gelnique™ a good option that means 'no swallowing pills.' Developed by Watson Pharmaceuticals, Gelnique™ has the same active ingredient that is available as oxybutynin tablets. The nice thing about the gel is that it gets absorbed through the skin and the active ingredient does not get metabolized in the liver which decreases potential side effects of dry mouth and/or constipation, according to Watson. It dries quickly, is clear and odorless. Gelnique™ touts few side effects which included dry mouth and some site reactions (redness, etc.) and no serious adverse events were reported in clinical trials of this drug

in this form. So, how do you use it, you ask? You apply a prescribed amount once daily to the thigh, abdomen, upper arm, or shoulder. A 1-gram dose of 100 mg/g will deliver a consistent dose of oxybutynin transdermally (through the skin) over a 24-hour period of time. It is well tolerated and has been shown to have strong efficacy.

Watson is a leader in the field of Urology, having also just received the 'go ahead' by the FDA to begin marketing its new treatment, Rapaflo™, which is indicated for BPH (benign prostatic hypertrophy).

Whenever looking at medication profiles for our consumers, it is important to look at potential side effects. Medications that have low anticholinergic effects are going to be a better choice because there will be less cognitive impairment for our consumers. Anticholinergic effects can cause our consumers to have more limited function than normal and this is a problem. Be aware of drug side effects!

CHECKING IN MEDICATIONS

Whether you are getting your medications in a monthly cycle fill (where most of your consumers' meds come all at once just before the beginning of a month)...or you get medications 'on demand' (you call us for a med, we send you the med)...you should have a system for checking in the medications that you receive to insure they are exactly what you ordered and what the consumer is needing. Many nurses do this job themselves, but in some organizations Team Leads, QMRPs and others may do a first check or all of the med check-in process. All the more reason to have a system. Teach your staff the preferred system also and make sure they follow it. Preparing a checklist as a reminder of all steps is a good idea. Remember, med errors can happen in many different ways and if we can decrease the chance of errors by having more checks in our systems along the way, then there is less chance that an error will occur.



Things to remember and include into your system for checking in medications:

- When medications are delivered to the home, have a system for who is responsible for checking in the meds at the door or

as soon as possible thereafter. This first QUICK look is to make sure that all meds delivered are, indeed, for the consumers in that home. If there is anything labeled for someone not in the home, notify the Pharmacy right away.

- Don't try to do this with a house full of busy consumers. Do it when they are asleep, after they have left for day programming or when they are with other staff doing activities that allow you to pay attention to what you are doing.
- Get all bubblepacks, bottles, and other medications that are to be checked in....put in one stack on the table.
- MAR and Physician Orders in front of you.
- Start at the top of the MAR with the first med. Read the order (out loud is good—it helps the info stick).
- Find the packaged medication that matches.
- Now compare each of the '5 RIGHTS'—

Right consumer, Right med, Right dose, Right time(s), Right route—look at the bubblepack and the MAR, comparing all items (again...out loud is good).

- Place the medication that you just checked in, separately from the others.
- If you find any discrepancy with any of the '5 RIGHTS', start over and repeat the process. If it is still wrong, find the problem. Follow up immediately to insure that errors are corrected and a wrong medication or dose is not given.
- Visualize each bubble of each bubblepack and insure the correct number of pills is in each bubble.
- Make a check mark on the MAR next to each medication as you check all of the 'RIGHTS' between the MAR and actual medication.
- If anything is missing that the consumer will need, call the pharmacy immediately so that it will be sent immediately.
- FINDING DISCREPANCIES: If you find a medication that does not match your MAR for that med, try to figure out the discrepancy before calling the pharmacy.

Where to start? Here are some clues:

- * Go to the original Physician's

Order—does it match?

*Check the previous month's MAR to see if a new order was written in that did not get transcribed onto the next month.

*If you can't figure it out, call the Pharmacy....who should have all of the orders (if they were faxed).

*If an order was not faxed that should have been, you will catch it here and you can still fax it in. In this instance, you may be asked to return the medication to the pharmacy.

- Pull out any medication that there is a discrepancy about. Do NOT put it back in with the scheduled meds until you clear up the problem.
- Non-cycle fill medications and supplies would not normally be delivered with the cycle fill medications. If you need these items (birth control, inhalers, creams,



ointments, eye or ear drops, blood glucose testing supplies, etc.) you will need to order them PRIOR to them running out. Develop a system weekly (we suggest Wednesday so no problems running out of meds on the week-ends) for checking all meds and supplies that "run out" and are not cycle filled. Order by noon on Wednesday so you have them before the weekend. (No phone calls saying "we ran out of test strips"....Yeah!)

- After checking in, store the medications by consumer using a system that makes sense to you and your staff (generally organizations store meds by consumer and by med pass time).
- Store liquids, sprays, etc. separately from pills—these should be stored upright to avoid spillage, with caps tightly secured.
- Some organizations individually bag their inhalers, sprays, ointments, etc. If your organization does this, you must insure the bags are kept clean! Replace bags when soiled.
- Keep the medication storage area clean. If it is a closet, a cupboard, or an actual med room, the area should be free of contaminants. Do not store meds in the coat closet with boots, shoes, gloves and extra house supplies.
- Medication area LOCKED!
- Remember that MEDICATION ERRORS can occur at any point in the process of dealing with medications....from the Physician's Order to communication with the Pharmacy, to dispensing, to delivery, to checking in, through administration of the medication to the consumers. We all have our piece of the puzzle to contribute so the final picture is a positive one.



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THE POST SCRIPT

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All articles to be considered for submission to this newsletter should go to Georgia Swank at the above email address. We welcome your comments and ideas!

National DDNA Conference

May 9-12, 2009

In May 2009, Developmental Disabilities Nurses and others in the DD field, will converge on Orlando, Florida for education and networking with healthcare professionals from around the U.S. If you have never experienced a DDNA National Conference, then this year should definitely be your turn to go. It is some of the best DD education available and there are 3 1/2 days of it! Almost as beneficial as the education is the incredible opportunity to network with other DD Nurses and compare notes about what people are doing in their organizations that could be a catalyst in your organization to improved supports, advocacy, and quality of life for your consumers.

Get online and go to www.ddna.org for all the information you will need to register to attend. You can also find out about vendor opportunities if you are a vendor. The Conference will be held at the beautiful Loew's Royal Pacific Resort in Orlando, FLA. This year the National DDNA will be combining with the AADMD (that's American Academy of Developmental Medicine and Dentistry) to include more topics related to the medical aspect and how physicians and nurses can create synergy in providing support for individuals with intellectual and developmental disabilities. The cost is \$545 for a member of DDNA for the Pre-Conference and Conference. It is well worth this cost. If you need assistance in presenting this to your supervisor, go to the DDNA website (above) and complete the document on the main page, filling in costs and names, and turn this in. It will assist you in making your request professionally and state the case for why this is a vital endeavor for you, as a DD Nurse, to attend.

Medication Prior Authorizations

You are checking in medications for your consumers and 2 medications are missing and they should be there. You call the Pharmacy and are told that these 2 medications require a Prior Authorization from the doctor. The Pharmacy tech states that you were sent faxes to pass on to the doctor stating what needed to be done 2 days ago. You do not see them on the fax machine so you call your supervisor who immediately knows what you are talking about. She says "Yes, those were sent to Dr. Dunn the same day." Should you relax at this point? Is your work done here? Not if you want to get those meds, it's not. Call the doctor's office and ask about the status of the PA. Stay on it until the Pharmacy confirms it was received.

We all deal with this situation regularly since the advent of Prior Authorizations for so many medications in the past few years. Why do we have PAs? What is the point? Although many nurses, pharmacists, physicians, and customers would answer that the point is to drive us all crazy!.....that was not the original intention.

Prior Authorization was created as a cost-savings feature of your prescription drug plan. This could be Medicaid, Medicare Part D (and associated Prescription Drug Plans), or private insurance Prescription Plans. Since some medications require a PA, patients are selectively steered to other, less expensive medications that (hopefully) will be just as effective for their conditions. If you receive a PA request and it

is denied by your insurance company for payment, then you always have the option of switching to an alternative medication or paying for the original medication out-of-pocket. **The Pharmacy will not send out a medication that has not been approved for payment by your insurance plan. We do not want you to get caught paying for this if there is another option that you would prefer. We let YOU make that decision.** The criteria for what drugs require a PA generally fall into certain categories:

- Brand name drugs that have a generic available
- Very expensive medications
- Drugs usually covered by your insurance, but they are prescribed at a dose higher than normal per guidelines
- Drugs for cosmetic reasons (such as hair growth)
- Drugs not usually covered but the physician states they are medically necessary and no other drugs would work

If you want to know what medications require a PA for your plan, you can Google the name of your drug plan and find this on the internet. Each PDP lists drugs requiring Prior Authorization.