#### **MEDICINES**

## What to Know About Medicines Before and After Transplant

To help prevent problems and keep your child's liver healthy, you need to know your child's current medicines. The transplant team (including the doctors and nurses) will work with you to improve your understanding of your child's medicines and the importance of giving them as directed. The team will help you to decide on the best times to give your child his/her medicines. To ensure that the medications are given correctly, we need your help in supervising administration of ALL medicines. Many pre-teen and adolescents will say that they are taking their medicines, but they are not. We will work with you and your child beginning at age 10 to develop strategies to help them develop independence, but until the team and you agree together that they are able to take medicines without supervision, we ask for your help in making sure all doses of medicines are taken. Even though they may feel that they are at an age to understand the importance of the medicines and are responsible, it is critical to your child's health and wellbeing that you, as a parent (caregiver) still supervise.

You are encouraged to keep a list with you of all current medicines (this can be either a hand-written list or a printed list such as the one we hand out in clinic) that your child is taking. This list should also include any over-the-counter, herbal medicines, or supplements. Since medicines are frequently adjusted or changed to meet the medical changes of your child, it is important that you update your list of medicines after each change (especially when these are done between clinic visits). Changes will be necessary before you finish all the medicines in a bottle. There will be times that the medicine instructions you have been given over the phone or in clinic are not the same as what is written on the prescription bottle. Your medicine list should include the following:

- Name of the medicine
- Concentration of the medicine if it is a liquid or compounded medicine. Example: 1 mg/ml, 15 mg/5 ml. Liquid medications are reported as both milligrams (mg) and milliliters (ml). These values are not the same and care should be taken not to confuse them.
- Dose of the medicine. Example: give 10 mg. Don't just list 1 ml. Many of the compounded medicines are compounded differently by pharmacies. It is important to note that they may mix (compound) it differently than what we have requested. If you get a new prescription, please let us know the concentration on the bottle. As an example, we may request a concentration of 60 mg/ml, but the pharmacy may make it up as 50 mg/ml.
- How often the medicine should be taken. Example: 10 mg daily (or 1 time per day) or 10 mg twice a day or every 12 hours.

## Important Information to Know About the Medicines:

- The brand name and generic name of the medicine
- When to give each medicine
- How to give them
- Reason for giving that medicine to your child
- Major side effects from the medicine
- What food or other medicines should be avoided when giving the medicine
- What to do if you miss a dose
- When and how to order refills
- What the medicine looks like

## You Should Know the Following About Storing Medicines:

- Store in the original containers.
- Keep the medicines tightly capped.
- Store them in a cool, dry place away from direct sunlight.
- Do not store in an area that has too much moisture such as the bathroom. Moisture can make them lose their strength.
- Keep all medicines out of the reach of children.
- Do not let the liquid medicines freeze if they require refrigeration.
- Do not store the medicine in the refrigerator unless instructed by the pharmacist.
- Give the medicine as directed each day at the same time.
- Do not crush or cut the tablet, capsule or caplet unless instructed to do so.

# You Should Call the Transplant Team About the Medicines if:

- Your child cannot take his/her medicines for any reason.
- Your child develops a rash, fever, nausea, vomiting, diarrhea or any unusual symptoms.
- You are not sure what dose to give your child.
- The medicine looks different when you picked it up from the pharmacy than it did other times you picked it up (received it) from the pharmacy.
- You believe your child needs an over-the counter medicine, such as pain relievers, cold medicines, etc.

- Another doctor prescribes or changes any of your child's medicines.
- You have any doubts or questions about your child's medicines.
- You need a refill of any of your child's medicines.

## You Should Be Aware of the Following Related to Refills of Your Child's Medicines:

- Refills should be obtained at your child's clinic visit. Ask the transplant team for any prescriptions which will run out before the next clinic visit.
- Plan ahead by always checking prescription bottles for the number of remaining refills. If in doubt, ask the pharmacist.

You Should Know Do not run out of medicines!

- Call the pharmacy to request refills at least one week before the medicines are gone. Most mail order pharmacies require at least two weeks processing your child's medicine refill.
- Prescriptions can be written for either a one-month or a three-month supply. The choice is determined by the patient's insurance coverage.
- Mail order pharmacies provide a three-month supply. You may pay a reduced co-pay for the three-month supply, which could help reduce out-of-pocket expenses. Use of mail order pharmacies depends upon your insurance coverage.
- Mail order pharmacies require a written prescription which can either be mailed by you or faxed by the transplant office.
- If you use a mail order pharmacy, you also will need a local pharmacy for short-term medicines. When you start a medicine, fill it locally for one month and then mail a prescription to the "mail-order pharmacy" which will start delivery in time for when you would run out in one month.
- Most non-liquid medicines are good for one year. Many **liquids** are only good for one to four weeks after compounding. The pharmacist will inform you how long a liquid medicine is effective. ALL medicines should be taken as directed by the transplant team.
- If your child is planning to be away from home during medicine time, you should bring his/ her dose(s) of medicine with you. This is to ensure you stay on time with your medicine.
- You should always bring your child's medicines with you when traveling, whether it is a short or a long trip. When traveling by plane, ALWAYS carry the medicines in your carryon bag instead of packing them in your checked bag. For liquid medicines, put all original bottles in a zip-lock bag for inspection.

- If your child is out of medication refills (the number of refills left can be found on the prescription bottle), contact the Pediatric Liver Transplant office during normal business hours or send a medication refill request through the patient portal. You will need to provide the name of the medication that you need refilled and the pharmacy that you would like the refill sent too.
- If your child's medication has refills available, contact the pharmacy the medication is prescribed at to request a refill.
- If you fill with University of Michigan's Transplant Specialty Pharmacy, call (866) 946-7695 and discuss with a pharmacy tech which medications you need filled and shipped.
- Please allow a minimum of three days for refill requests to be processed. While a sincere effort will be made to process requests in less than three days, it cannot be guaranteed. If your child's medicines are a compounded liquid, your pharmacy will need at least a TWO-DAY notice and often more. Compounding medicines takes several hours to process.
- The Pediatric Liver Transplant office can only refill those medicines that have been prescribed by our office. For all other medicine refills, you will need to contact the doctor's office that ordered the medicine for your child. This is to ensure that the medicines and their potential side effects are being monitored appropriately. Also, if your child is not responding to the medicine, they may need adjustments that we can't do in the transplant clinic. An example would be medicines for asthma or allergies.

#### What You and Your Child Need to Know About the Medicines

The success of a transplant depends on the proper use of anti-rejection medicines. For this reason, your child cannot be discharged from the hospital until you, as family members, can demonstrate a basic understanding about all the medicines. It is important to give all of your child's medicines exactly as they are prescribed and on time in order to protect the new liver from rejection. Sometimes you will be away from home when it is time to give your child the anti-rejection medicines. Therefore, you will need to get into the habit of carrying the medicines with you so that your child's medication schedule will not be interrupted. Some of the medicines require refrigeration, so a cooler with ice may be necessary for transportation.

As your child grows and becomes older, he/she will be taught this same information in order to care for themselves as adults. For the teen/adolescent recipients, they will be taught how to set up their medicine planner with the discharge medicines before leaving the hospital for home.

The transplant office should verify that it is safe to take **ANY** medicine other than the ones prescribed to you by your transplant doctor before giving them to your child. Many of the antirejection medicines have interactions with other medicines. We give you a list of some of these interactions in clinic. These interactions can cause the anti-rejection medicines to be either too strong or too weak and can lead to a rejection episode. The **ONLY** thing that can be given without prior approval from the nurse coordinator is Tylenol (or generic acetaminophen). This includes any form of herbal supplements, weight loss, and over-the-counter medicines.

# NEVER stop giving medicine, skip doses, or decrease the dosage of the prescribed medicines on your own.

Doing so can risk your child's health. If your child has missed any of the doses of his/her medicines, contact your nurse coordinator immediately for instructions. Do not try to catch up by taking two doses of the medicine. When in doubt as to what to do, give the transplant office a call.

#### You Should Know

Never stop giving medicine, skip doses, or decrease the dosage of the prescribed medicines on your own.

The reality is that children may vomit after taking their medicines. Here are guidelines to follow if this should occur:

- If your child vomits within 30 minutes after the dose, the entire dose must be given again.
- If your child vomits within 30 minutes to one hour after the dose, half of the dose must be given again.
- If your child vomits more than one hour after the dose, there is no need to give the dosage again.
- If your child **cannot** keep any medicines, food or fluids down, **you must** contact the transplant office immediately.

# Anticipated Cost of Medicines - Per Month

Proper use of prescribed medicines is one of the most important ways for a patient to maintain a healthy liver. Unfortunately, these medicines are very expensive – but necessary. It is very important to maintain your insurance coverage for your child's medicines. Lapse in coverage can be extremely costly to you. If you have concerns about your insurance coverage for your child's prescriptions, you are asked to contact the transplant social worker and financial coordinator who will assist you in developing a plan.

## Anti-Rejection Medicines

Your child will take at least one anti-rejection medicine for the rest of his/her life. Antirejection medicines are also called immunosuppressive drugs. These drugs decrease the body's ability to fight off what it sees as foreign. The medical team attempts to minimize the amount of immunosuppression while preventing rejection. This allows an appropriate balance for your body to fight infection without rejecting the transplanted organ.

Since the chance of rejection is highest immediately following the transplant surgery, patients receive the greatest number of drugs and in higher dosages shortly after surgery. As the time after surgery increases, it is likely a patient will take fewer drugs and in smaller doses. By the end of the first year, many patients remain on only one anti-rejection medicine.

There are four types of anti-rejection medicines that are commonly used. Each type works differently in the body to prevent rejection, but all affect T-cell (lymphocytes) function. Patients often take a combination of the following:

- Tacrolimus (Prograf<sup>®</sup>), Tacrolimus XR (Envarsus XR<sup>®</sup>) or Cyclosporine (Neoral<sup>®</sup> or Gengraf<sup>®</sup>)
- Mycophenolate Mofetil (CellCept<sup>®</sup>), Mycophenolate Sodium (Myfortic<sup>®</sup>) or Azathioprine (Imuran®)
- Prednisone
- Sirolimus (Rapamune®) or Everolimus (Zortress®)

# Tacrolimus (Prograf®), Tacrolimus XR (Envarsus XR®), or Modified Cyclosporine (Neoral® or Gengraf®)

Tacrolimus and cyclosporine are similar in their effects on white blood cell function; they are called calcineurin inhibitors. Your child will take either tacrolimus or cyclosporine, but will never take both at the same time. Tacrolimus (Prograf®) and modified cyclosporine is taken twice a day, 12 hours apart. Tacrolimus XR (Envarsus XR®) is taken once a day in the morning. Infants and small children may require three doses per day of the medicine because of their higher rate of metabolism. As the time from transplant increases, they can eventually move to twice a day dosing.

It is important to maintain therapeutic blood levels as this is the only way to tell if your child is on enough medicine. Blood concentrations are measured at their lowest level, which is referred to as a "trough level." For example, if the tacrolimus (Prograf®) is taken at 8:00 p.m. on Monday night, you need to have your child in the lab on Tuesday at 8:00 a.m. to have the blood drawn. If tacrolimus XR (Envarsus XR®) is taken at 8:00 a.m. on Monday morning, you need to have your child in the lab on Tuesday at 8:00 a.m. to have blood drawn.

Once the blood has been drawn, you should give your child his/her morning dose of tacrolimus. Measuring trough levels reflects whether adequate blood levels are being maintained. Based on this trough level, the transplant team will adjust the medicine.

When taking tacrolimus or cyclosporine your child should not eat or drink grapefruit (juice), since it increases the amount of the medicine absorbed into the blood stream. There are several tropical fruits that should not be consumed including star fruit, pomegranate, pomelo, and papaya. Juices and fruits that are OK to use include grape, orange, apple, cranberry, tangerine and pineapple.

# Tacrolimus (Prograf® or Generics)

If cost is an issue and you or your insurance state that your child must change to a generic brand, the following actions need to be taken:

- Notify the Transplant Office before the change.
- Obtain drug levels within two weeks of beginning the new drug.
- Do not interchange different generic brands.

Dose Strengths: Liquid 0.5 mg/ml

> 0.5 mg capsule 1 mg capsule 5 mg capsule

If your child takes the capsules, they must take them whole.

Do not cut, crush or chew them.

Frequency: Most common is twice a day, 12 hours apart.

Infants and small children may require three times a day,

eight hours apart.

The medicine must be given on time.

Possible Side Effects: Kidney toxicity

High blood pressure

High blood sugar/diabetes

Tremors, tingling and/or shaking hands

Nausea, vomiting, diarrhea High potassium levels

Low magnesium levels

Hair loss

Increase chance for infections

Post-transplant lymphoproliferative disorders

The side effects of tacrolimus are usually dose-related. They generally get better or disappear as the dose is lowered over time. When your child comes to the clinic or has local lab studies drawn, we will continue to monitor the level of tacrolimus in the blood and make adjustments in the dosage based on these levels.

Individual Dosing: Dose varies based on drug levels

Higher doses are usually required shortly after transplant or

after an episode of rejection.

### Tacrolimus XR (Envarsus XR®)

If cost is an issue and you or your insurance states that your child must change to the tacrolimus (Prograf<sup>®</sup>) formulation, the following actions need to be taken:

Notify the Transplant Office before the change.

Obtain drug levels within two weeks of beginning the new drug.

Dose Strengths: 0.75 mg tablet

> 1 mg tablet 4 mg tablet

The tablet must be taken whole. Do not cut, crush or chew them.

Frequency: Once a day in the morning, 24 hours apart.

The medicine must be given on time.

Possible Side Effects: Kidney toxicity

High blood pressure

High blood sugar/diabetes

Tremors, tingling, and/or shaking hands

Nausea, vomiting, diarrhea High potassium levels Low magnesium levels

Hair loss

Increase chance for infections

Post-transplant lymphoproliferative disorders

The side effects of tacrolimus are usually dose-related. They generally get better or disappear as the dose is lowered over time. When your child comes to the clinic or has local lab studies drawn, we will continue to monitor the level of tacrolimus in the blood and adjust the dosage based on these levels.

Individual Dosing: Dose varies based on drug levels

Higher doses are usually required shortly after transplant or after an

episode of rejection.

## Modified Cyclosporine (Neoral®, Gengraf®, or Generics)

Neoral® and Gengraf® are two brands of modified cyclosporine that are frequently used. There are several other generic brands that are available by manufacturers such as Pliva and IVAX.

If cost is an issue and you or your insurance state that your child must change to a generic brand, the following actions need to be taken:

Notify the Transplant Office before the change.

Obtain drug levels within two weeks of beginning the new drug.

Do not interchange different brands.

Dose Strengths: Liquid 100 mg/ml

> 25 mg capsule 100 mg capsule

If your child takes the capsules, they must take them whole.

Do not cut, crush or chew them.

Taken twice a day, 12 hours apart Frequency:

The medicine must be given on time.

Possible Side Effects: Kidney toxicity

High blood pressure

Tremors, tingling and/or shaking hands

Nausea, vomiting, diarrhea High potassium levels Low magnesium levels Increased hair growth Overgrowth of gums

Gout

Increase chance for infections

Post-transplant lymphoproliferative disorders

Individual Dosing: Dose varies based on drug levels

Higher doses are usually required shortly after transplant

## Mycophenolate Mofetil (Cellcept<sup>®</sup>), Mycophenolate Sodium (Myfortic<sup>®</sup>), or Azathioprine (Imuran<sup>®</sup>)

These drugs work by inhibiting production of white blood cells (WBC). Many patients are weaned off mycophenolate mofetil or mycophenolate sodium by the end of the first year after a transplant. Azathioprine is not usually a first-line drug, but may be used if the patient is unable to tolerate mycophenolate mofetil or has an autoimmune disease.

# Mycophenolate Mofetil (CellCept® or Generics)

Dose Strengths: Liquid 200 mg/ml

> 250 mg capsule 500 mg tablet

If your child takes capsules or tablets, they must take them whole.

Do not cut, crush or chew them.

Frequency: Taken twice a day, 12 hours apart

The medicine must be given on time.

Possible Side Effects: Diarrhea

Nausea

Abdominal cramping, bloating

Low white blood cell and platelet counts

Increase chance for infections

Post-transplant lymphoproliferative disorders

Individual Dosing: Dosing is according to weight and WBC/platelet counts.

> Dose may be adjusted for infections or low WBC/platelet counts. Usually given with either tacrolimus or modified cyclosporine.

## Mycophenolate Sodium (Myfortic® or Generics)

Dose Strengths: 180 mg delayed-release tablet

360 mg delayed-release tablet

The tablets must be taken whole Do not cut, crush or chew them.

Frequency: Taken twice a day, 12 hours apart

The medicine must be given on time.

Possible Side Effects: Diarrhea

Nausea

Abdominal cramping, bloating

Low white blood cell and platelet counts

Increase chance for infections

Post-transplant lymphoproliferative disorders

Individual Dosing: Dosing is according to weight and WBC/platelet counts.

> Dose may be adjusted for infections or low WBC/platelet counts. Usually given with either tacrolimus or modified cyclosporine.

## Azathioprine (Imuran® or Generics)

Dose Strengths: Liquids can be compounded by a specialty pharmacy (this is not

advised as levels are too variable)

50 mg tablet

Frequency: Usually given once a day

Possible Side Effects: Nausea, vomiting, diarrhea

Low WBC counts

Increased chance for infections

Post-transplant lymphoproliferative disorders

Individual Dosing: Usual dose varies with weight and the reason it is being used.

Use with tacrolimus or cyclosporine

#### Prednisone

Prednisone is a generic name for a corticosteroid used as anti-inflammatory drugs. We use this medicine to help prevent rejection from occurring in the first few months after transplant. Prednisone is usually weaned off within three to six months after transplant unless your child has an autoimmune disease. It is used again with episodes of rejection.

Dose Strengths: Liquid 5 mg/5 ml or 5 mg/ml

1 mg tablet 2.5 mg tablet 5 mg tablet 10 mg tablet 20 mg tablet 50 mg tablet

This medicine can be crushed and mixed with liquid or food. It **must** be taken with food to prevent stomach upset or ulceration.

Frequency: Usually once a day in the outpatient setting; sometimes every other day

Possible Side Effects: Diabetes, increased blood sugar

High blood pressure

Mood swings Trouble sleeping

Acne

Swelling of face (moon shape), hands and feet

Sodium and water retention

Increased cholesterol

Increased appetite and weight gain

Bone loss, brittle bones Thin arms and legs Muscle weakness

Sweating

Vision changes, cataracts Poor wound healing

Increased susceptibility to infections

The side effects may be more noticeable during the tapering process.

Individual Dosing: Steroid is administered as IV Methylprednisolone immediately

following the transplant instead of oral prednisone. At first, it is given every six hours. Before discharge, dosing will convert from IV

to oral tablets or liquid.

To Taper Prednisone: Decreasing the dose **should only** be done under the care of the

transplant team.

## Sirolimus (Rapamune®) or Everolimus (Zortress®)

Sirolimus and everolimus are called mTOR inhibitors and work by inhibiting production of white blood cells. These drugs are not usually first-line drugs, but may be used if the patient is unable to tolerate other anti-rejection drugs.

# Sirolimus (Rapamune® or Generics)

Dose Strengths: Liquid 1 mg/ml solution

> 0.5 mg tablet 1 mg tablet 2 mg tablet

Frequency: Taken once a day in the morning

Possible Side Effects: Low red blood cell count

Low platelet count

Low white blood cell count

High cholesterol and triglyceride

Individual Dosing: Dose adjustment is made based on drug levels.

# Everolimus (Zortress®)

Dose Strengths: 0.25 mg tablet

> 0.5 mg tablet 0.75 mg tablet 1 mg tablet

Frequency: Take twice a day, 12 hours apart.

Possible Side Effects: Low red blood cell count

Low platelet count

Low white blood cell count

High cholesterol and triglyceride

Individual Dosing: Dose adjustment is made based on drug levels.

#### **Medicines to Prevent or Treat Infections**

After transplant, patients are at greater risk of infection. These infections can come from bacteria, fungi or viruses that are normally found in the environment. Since transplant patients take anti-rejection medicines that lower their resistance to infection, they also are given several medicines to help prevent infections.

### Anti-Bacterial

### Sulfamethoxazole/Trimethoprim (brand names: Bactrim, Septra, Cortimoxazole)

Dose Strengths: 200 mg/40 mg per 5 ml suspension

400 mg/80 mg single-strength tablet

Frequency: Taken once a day

Individual Dosing: Is given for a total of 30 days after transplant

Side Effects: Nausea, vomiting

Skin rash

Low white blood cell counts

Precautions: If your child is allergic to sulfa, a different medicine (pentamidine

inhalation, dapsone tablets, or atovaquone suspension) will be given as prevention. This medicine can cause an increased sensitivity to sun.

Sunscreen should be used.

## Anti-Fungal

### Nystatin

Dose Strengths: Swish and Swallow (S/S) 400,000 units (4 ml)

Frequency: Use four times daily

Individual Dosing: Is given for a total of 30 days after transplant, but may be given longer

if your child is experiencing symptoms of "thrush" in the mouth.

Swab the mouth with the liquid or swish and swallow.

Do not allow your child to eat or drink for at least 15 minutes after

the dose.

Side Effects: Nausea, diarrhea

## Fluconazole (Diflucan® or Generics)

Dose Strengths: Liquid 40 mg/ml

> 50 mg tablet 100 mg tablet 200 mg tablet

Frequency: Used once per day

Individual Dosing: Is given for a total of 30 days after transplant

May be given instead of nystatin

Side Effects: Nausea, vomiting

> Diarrhea Headache Rash

Raises tacrolimus or cyclosporine levels

#### Anti-Viral

CMV (cytomegalovirus) is a common herpes virus most people have had as a child. The usual symptoms of CMV infection are "flu like symptoms." Many younger children have not been exposed to CMV and are at great risk of developing the infection after a transplant. Before transplant, patients have a blood test to identify the presence of an antibody to CMV which indicates that they have previously had the infection. The results of this test (and a similar test given to the organ donor) determine which anti-viral medicines are prescribed to prevent CMV or other herpes infections. The most commonly used is Valganciclovir (Valcyte<sup>®</sup>).

## Valganciclovir (Valcyte<sup>®</sup>)

Dose Strengths: Liquid 50 mg/ml

450 mg tablet

Do not cut, crush or chew them.

Frequency: Used once per day

Individual Dosing: Is given for a total of 30 to 90 days after transplant

Side Effects: Nausea

Vomiting

Decreased white blood cell counts

#### **Other Medicines**

Frequently, it may be necessary for children to take medicines that are new to them. Antirejection medicines and surgery can cause a patient to have high blood pressure, high blood sugars, stomach problems, and electrolyte imbalances. Theses conditions can be temporary or permanent. The following are examples of medicines that may become necessary.

## **Medicines for Electrolyte Imbalances**

Sometimes medicines can cause imbalances in the body's electrolytes, the substances needed by your body to maintain fluid balances and many other functions. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body. When electrolytes are higher or lower than normal range, medicines can be used to correct the imbalance.

## Magnesium Oxide/Magnesium Gluconate (Magonate<sup>®</sup>)

Magnesium oxide or magnesium gluconate is used to treat a low magnesium level.

Dose Strengths: Magonate® (1 gm/5ml solution)

Tablets in various strengths

Frequency: Used once to twice daily

Separate from mycophenolate mofetil or mycophenolate sodium

by at least two hours

Individual Dosing: Is given depending on need for this medicine

Side Effects: Diarrhea, abdominal cramping

Muscle weakness

High magnesium levels Low blood pressure

### Sodium Bicarbonate, Sodium Citrate, Citric Acid (Bicitra®)

Dose Strengths: Bicitra® (1mEq/ml bicarbonate)

Sodium bicarbonate 325 mg and 650 mg tablets

Frequency: Used once per day and up to five times per day as treatment

Individual Dosing: Is given depending on need for this medicine

Side Effects: Abdominal distention, gas

Swelling of the hands and feet

Low levels of sodium, potassium, and/or calcium

## **Anti-Hypertensive Medicines (Blood Pressure)**

High blood pressure may be a result of the surgery and the anti-rejection medicines. The high blood pressure may be a short-term or a long-term problem. Not controlling the high blood pressure can lead to long-term effects on the kidneys and other organs. Before discharge from the hospital, you will be taught how to take your child's blood pressure. Most patients are sent home with a blood pressure machine. It is important to record the blood pressure readings and contact the transplant team with blood pressures that are out of the ideal range. If the blood pressure remains elevated even with the current medicine, adjustments may be necessary. The blood pressure record should be reviewed at each clinic visit by the transplant team.

There are different potential anti-hypertensive medicines that could be used to control the high blood pressure. There might be time when more than one of these medicines may be used at once.

## Isradipine (DynaCirc®)

Dose Strengths: Compounded liquid – 1 mg/ml

> 2.5 mg tablet 5 mg tablet

Frequency: Used once per day and up to four times per day

Individual Dosing: Is given depending on the blood pressure readings

Side Effects: Headaches, dizziness

Swelling in the hands and/or feet

Palpitations Flushing

Low blood pressure

Nausea

Amlodipine (Norvasc®)

Dose Strengths: Compounded liquid – 1 mg/ml

> 2.5 mg tablet 5 mg tablet 10 mg tablet

Frequency: Used one to two times per day

Individual Dosing: Is given depending on the blood pressure readings Side Effects: Headaches, dizziness

Irregular heartbeat

Fatigue Nausea

Low blood pressure

Lisinopril

Dose Strengths: Compounded liquid – 1 mg/ml

> 2.5 mg tablet 5 mg tablet 10 mg tablet 20 mg tablet 30 mg tablet 40 mg tablet

Frequency: Used one to two times per day

Individual Dosing: Is given depending on the blood pressure

Side Effects: Rash

> Nausea, vomiting Dizziness, headaches

Cough

High potassium levels Low blood pressure

#### **Diuretics**

Some patients after having a liver transplant will still need to use a water pill (diuretic) such as furosemide (Lasix®). The drug will be decreased and stopped as swelling decreases (ascites and swelling in the legs). It can take several weeks to months for the swelling to go away.

# Acid-Reducing Medicines

These medicines protect the digestive system and will be prescribed as long as your child needs them. Once some of the medicines (Prednisone or CellCept®) are tapered (decreased), patients often don't need anti-ulcer medicines and will be asked to stop using them. Examples of these medicines include Prevacid<sup>®</sup>, Pepcid<sup>®</sup>, Protonix<sup>®</sup>, Prilosec<sup>®</sup> and Nexium<sup>®</sup>. These medicines come in liquid or tablet/capsule form.

## **Medicines to Prevent Clotting**

Blood thinners such as a baby aspirin will be given to your child to prevent the blood vessels to the liver from clotting after transplant. Aspirin must be given with food or after meals to help prevent stomach upset. The duration of aspirin will be determined by the transplant team.

#### **Medicines to Increase Bile Flow**

### Ursodiol (Actigall®)

This medicine may have been started pre-transplant to help with itching (pruritis). After transplant, this medicine is used to keep the bile thin so it does not clog up or obstruct in the common bile duct. The duration of ursodiol will be determined by the transplant team. There are very few side effects associated with this medicine.

Compounded liquid – 20 mg/ml, 25 mg/ml, 60 mg/ml Dose Strengths:

> 250 mg tablet 300 mg capsule

Frequency: Used one to two times per day

Individual Dosing: For most children after transplant, it is usually only given for

three months. For children that have developed a bile leak or bile

stricture (narrowing), the medicine will be used long-term.

# **Medicines to Treat Hyperglycemia/Diabetes**

#### Insulin

Tacrolimus and prednisone can cause blood sugar to increase. Elevated blood sugars can sometimes be managed using an oral medicine such as glipizide, glyburide or several others. If oral medicines do not manage the elevated blood sugar, insulin may be necessary. Elevated blood sugar may be a short-term or a long-term problem. Long-term management of diabetes is managed through the patient's local doctor or by a diabetic team.

As prednisone and tacrolimus are decreased, blood sugars may come down. Therefore, it is important for you to closely monitor your child's blood glucose levels. Monitoring blood sugar levels at home requires a machine (glucometer) which is prescribed at the time of discharge. You will be instructed on the proper use of the glucometer and how to record and treat your child's blood sugar levels. It is important to bring the blood sugar record to all clinic visits to be reviewed by the transplant team.

## Over-The-Counter (OTC) Medicines

There are many medicines that do not require a prescription and can be purchased over the counter. These drugs are used to treat minor ailments and are generally safe to use. However, there are some OTC medicines that may cause problems in a post-transplant patient.

In selecting OTC medicines for these minor conditions, it is important to avoid any medicine that contains ibuprofen or naproxen because they can interact with anti-rejection

#### You Should Know

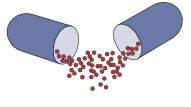
Do not take anything that contains ibuprofen or naproxen including Advil<sup>®</sup>, Motrin<sup>®</sup>, Naprosyn<sup>®</sup> and Aleve<sup>®</sup>.

medicines and cause kidney failure. Examples that contain ibuprofen or naproxen and should be avoided include Advil<sup>®</sup>, Motrin<sup>®</sup>, Naprosyn<sup>®</sup>, or Aleve<sup>®</sup>. The only medicine that can be used for fever or discomfort is acetaminophen (Tylenol®). It is important to read the labels on the medicines to know the content and dosage before giving these medicines to your child.

## The Safe Use of Acetaminophen

### Acetaminophen

Acetaminophen, commonly known as Tylenol®, is widely used for pain and fever in children as well as adults. Many prescription and over-the-counter pain and cold medicines contain acetaminophen,



and it is important that you do not take too much. In some cases, too much acetaminophen is taken because several medicines with acetaminophen are used at the same time. Taking too much acetaminophen can be harmful.

#### **Avoiding Acetaminophen Toxicity**

- Check the labels of all prescription and over-the-counter medications you take to see if they contain acetaminophen.
- Do not give more than the recommended daily dose of acetaminophen recommended by either your child's pediatrician or the transplant team.
- When adding up your daily acetaminophen dose, be sure to include all the acetaminophen you take in prescription and over-the-counter products.
- Carefully read the labels of children and infant forms of acetaminophen for dosage information; always use the measuring cup or spoon that comes with the medication.
- Do not use high doses of acetaminophen for a long period of time unless recommended by your hepatologist.

- Do not drink alcohol while you are taking acetaminophen. Heavy alcohol use may increase the risk of toxicity. All patients in the transplant process must not drink alcohol.
- Eat regular meals when taking acetaminophen.
- Ask your pharmacist or doctor before taking a new medication to screen for acetaminophen content or other drug interactions. If you have questions about a medication, please contact your tranplant nurse at **(877) 543-7789**, option 3.

You may take acetaminophen as advised above. Do not take NSAIDs (ibuprofen, naproxen Advil®, Motrin®, Naprosyn® or Aleve®) or aspirin, unless advised by a cardiologist and approved by your liver doctor.

## **Some Products That Contain Acetaminophen**

Some commonly used products that contain acetaminophen are:

- Acetaminophen (generic and Tylenol® brands) caplets, capsules, tablets, chewable tablets, liquids (Children's acetaminophen, Infant's acetaminophen), suppositories
- Actifed® A, Actifed® Cold and Sinus, Actifed® Plus
- AlkaSeltzer Plus Cold<sup>®</sup>, AlkaSeltzer Plus Cold and Sinus<sup>®</sup>
- Allerest® products
- Anacin<sup>®</sup>, Anacin<sup>®</sup> 3<sup>®</sup>
- Arthritis Foundation® Aspirin Free
- Benadryl® Allergy/Cold tablets
- Capital® with Codeine
- Comtrex® products
- Darvocet®
- Datril Extra®
- Drixoral® products
- Endocet®
- Excedrin® PM, Excedrin Migraine®
- Fioricet<sup>®</sup>, Fioricet<sup>®</sup> with Codeine
- Liquiprin<sup>®</sup>
- Lorcet<sup>®</sup>, Lortab<sup>®</sup>
- Midrin®

- Midol®
- Norco®
- Pamprin®
- Panadol®
- Percocet®
- Percogesic®
- Phenaphen® with Codeine
- Roxicet®
- Sineaid® Sinus medicine
- Sinutab® products
- Sominex® Pain Relief Formula
- St. Joseph's Aspirin-Free products
- Sudafed® Sinus products
- Tempra®
- Theraflu® products
- Tylenol Flu®, Tylenol PM®, Tylenol Sinus®, Tylenol Cold®, Tylenol Sore Throat®, Tylenol Allergy®, Women's Tylenol®
- Tylenol with Codeine #2, 3, and 4
- Tylox®
- Vanquish® products
- Vicodin®
- Wygesic®

Source: Department of Pharmacy Services, Drug Information Service, University of Michigan Hospitals and Health Centers

# **Drugs to Avoid**

There are many drugs that can interact with anti-rejection drugs. If you are taking cyclosporine, tacrolimus, sirolimus, or everolimus, you should check with the transplant team before taking any new prescription or over-the-counter medications. The following are some examples of drugs with significant interaction potential, however, this list does not include all of them.

CLASS	DRUG	COMMON TRADENAME	
Anti-infective drugs	Clarithromycin Erythromycin Telithromycin Amikacin Gentamicin Tobramycin	Biaxin® EES, Ery-Tab, E-mycin, ERYC Ketek™ — —	
	Nafcillin	_ _	
	Rifabutin Rifampin	_	
	Amphotericin B	_	
	Fluconazole Itraconazole Ketoconazole Voriconazole Posaconazole Isavuconazonium sulfate	Diflucan® Sporanox® Nizoral® VFEND® Noxafil® Cresemba®	
Anti-seizure drugs	Carbamazepine Phenobarbital Phenytoin	Tegretol® Luminal® Dilantin®	
Blood pressure lowering drugs	Diltiazem	Cardizem®, Cardizem CD®, Cartia XT®, Dilacor XR®, Dilt-CD®, Dilt-XR®, Diltia XT®, Taztia XT®, Tiazac®	
	Verapamil	Calan®, Calan SR®, Covera-HS®, Isoptin®, Isoptin SR®, Verelan®, Verelan PM®	
Pain killers	Non-steroidal anti-inflammatory drugs	_	

## **Nutritional Supplements**

It is generally recommended that your child receive a multivitamin supplement after transplant. This is particularly important if your child's nutritional status was poor before transplant, had a difficult recovery with complications following surgery, or if he/she has poor eating habits. If your child requires something more than a multivitamin, the dietitian will recommend this to you. In Michigan, it is also common to require a Vitamin D supplement because of our long winter.

#### **Diet Pills and Herbal Products**

It is strongly recommended that transplant recipients avoid taking any type of diet pill or herbal products, remedies, or teas. Prior to giving your child any of these products, it should be approved by the transplant team. Many of these products interfere with the transplant medicine and could lead to problems with the liver.

All transplant patients should avoid St. John's Wort because of its serious health risk.

## **Pregnancy After Transplant**

It is possible to have a healthy pregnancy and delivery after a liver transplant; however, these pregnancies are still considered high risk. The decision to become pregnant should be discussed with your transplant team, and it is important that pregnancies in transplant patients be managed by both your transplant doctor and a high-risk obstetrician. Pregnancy after a transplant should be planned, but if you become pregnant unexpectedly, you should let your transplant team know as soon as possible.

Potential complications of pregnancy after a transplant include:

- Pregnancy may increase the risk of rejection of your new liver. Thus, it is recommended not to become pregnant in the first year after transplant when the risk of rejection is the highest.
- There are higher rates of premature delivery and low birth weight in infants born to transplant recipients.
- There are increased risks for maternal complications such as preeclampsia (a medical condition that can occur during pregnancy and is characterized by high blood pressure and significant amounts of protein in the urine) in transplant recipients.

Medications commonly taken after a transplant may cause harm to the fetus if taken during pregnancy. Issues that are important to be aware of are listed below:

The use of mycophenolate (brand names CellCept® or Myfortic®) during pregnancy has been associated with a higher risk of miscarriage in the first three months, as well as birth defects. This medication should **NEVER** be taken during pregnancy.

- Certain blood pressure lowering medicines (ACE inhibitors and angiotensin receptor blockers) are also known to cause fetal harm and must be discontinued.
- Commonly used birth control methods may be less effective in combination with antirejection medications. Female transplant recipients MUST use a recommended effective contraception method (see table) while taking mycophenolate and for six weeks after stopping mycophenolate.
- A member of the transplant team will discuss the potential risks of mycophenolate with you and acceptable birth control options while you are taking it.
- If you discover that you are pregnant, **DO NOT** discontinue any anti-rejection medications without talking to your transplant doctor. Discontinuing anti-rejection medications can result in rejection or loss of the transplanted organ.

### ACCEPTABLE CONTRACEPTION METHODS — Choose One Option Option 1 Methods to Use Alone • Intrauterine devices (IUDs) Tubular sterilization • Patient's partner had a vasectomy Option 2 Choose One Hormone Hormone Methods (choose 1) Barrier Methods (choose 1) Method AND One AND Barrier Method Estrogen and Progesterone Diaphragm with spermicide • Cervical cap with spermicide Oral contraceptive pills Transdermal patch Contraceptive sponge Male condom Vaginal ring Female condom Progesterone only Injection Implant Option 3 Choose One Barrier Method from EACH column (must Barrier Methods (choose 1) Barrier Methods (choose 1) chose TWO methods) **AND** Diaphragm with spermicide Male condom • Cervical cap with spermicide Female condom Contraceptive sponge