

# TIPS

**University of Florida  
Glycogen Storage  
Disease Program**

**UF GSD Team  
Vol. II  
5-10-12**

<b>PAGE #</b>	<b>TOPIC</b>
3	Emergencies
3	Non-Emergencies
4	Cornstarch
5	Cornstarch
6	Nutrition
7	Vitamins
7	Oral Hygiene
7	When to Contact Your GSD Dietitian
8	Sugars
9	Surgery Letters
9	Labs & Ultrasounds
9	Scheduling
10	Supplies and Equipment
11	Travel
12	School
13	School
14	School
15	School
15	Sports
16	College
17	College
18	Insurance
19	Coverage & Authorization
20	Coverage & Authorization
21	Coverage & Authorization
21	Assistance in Finding Coverage
22	Fun
23	Fun
24	Disclaimer, Thanks, Dedication

## **EMERGENCIES**

### **WHEN TO GO TO THE EMERGENCY ROOM**

- Seizure
- Unresponsive
- When you feel it is necessary

### **WHEN TO PAGE DR. WEINSTEIN**

- Patient is going to the emergency room
- Lactates above 7.0
- Ketones above 1.5
- Glucose below 50mg/dL
- Patient being prescribed a medication and not familiar with its response in GSD patients
- Prolonged elevated lactates, ketones or hypoglycemic episodes

### **HOW TO PAGE DR WEINSTEIN**

- Dial 1-888-961-8985
- Enter your area code and number after the beep
- Hang up, so your line will not be busy
- If you have not received a return call within 15 minutes, page again, using a different phone if possible
- If you do not receive a return call, call 352-265-0111, and ask for the “pediatric endocrine fellow on call”

## **NON-EMERGENCIES**

### **RETURN CALLS**

- Please only call Dr. Weinstein at his office number or his pager number. Do not call the phone numbers that appear on Caller ID

### **CONTACT DR. WEINSTEIN**

- 352-273-5823-office
- weinsda@peds.ufl.edu

# **CORNSTARCH (cs)**

## **BRAND OF CORNSTARCH**

- We recommend Argo or Kingsford brand, in the US. Canada Starch or Benson's, in Canada, may also be used.
- These brands are made by the same company, have less fillers, and seem to hold blood glucose levels longer.
- At the time of purchase, check the container's seal to make sure the cs will be fresh.

## **WHERE TO PURCHASE CORNSTARCH**

- Grocery stores usually have the quickest rotation of products. Cornstarch can be found in the baking section near the flour.
- Larger quantities can be found at wholesale stores, (see Storage of Cornstarch), but containers over 1Kg/2lbs are not recommended.

## **STORAGE OF CORNSTARCH**

- CS should be stored in an air tight container.
- If purchased in plastic containers and factory sealed, the unopened cs should be good for up to 6 months.
- If cs is purchased in a bag or cardboard container, it should be good for up to 1 month.
- Once opened, cs should be good for up to two weeks from the date it was opened, if tightly sealed.
- Cornstarch should be kept at room temperature.
  - Do not store cs in the refrigerator.
  - Do not store cs in a hot vehicle.
  - If you are traveling in heat, place the cs in an insulated lunch box to help maintain its effectiveness.

## **CONTAINERS FOR PRE-MEASURED CORNSTARCH**

- It is best to use the smallest container that fits the recommended dose, to minimize the amount of cs residue left.
- Storage Options:
  - ♦ Specimen cups are readily available on line; search by the ounce size and non sterile
  - ♦ Plastic Freezer Canning Jars

# CORNSTARCH (cs)

## MEASURING

*Measuring cornstarch  
should always be as precise as possible*

**8 grams of cornstarch = 1 Tablespoon**

### **Measuring Spoon**

- The cs should be leveled off (unpacked) each time. Each person scoops differently, which varies the amount of cs.
- Always use the same measuring spoon; different styles of measuring spoons can vary the amount of cs.

### **Gram Scales**

- Purchase a scale that weighs to the tenth of a gram (0.1g); measuring by grams is more accurate than using measuring spoons.
- Compact gram scales can be found online for as little as \$15.00. (see Supplies and Equipment)

## MIXING CORNSTARCH

- Add liquid to the container of pre-measured cs and either shake with the lid on, or stir with spoon.
- It is very important to add the liquid and mix the liquid with the cs, **only when it's time for consumption**. As time passes, pre-mixed cs and liquid will lose its effectiveness. Mixed cs should be consumed immediately for best results.
- Consume the entire dose. Cornstarch may stick to the bottom if is not mixed well. If this happens, mix more liquid to ensure that the entire dose is consumed.
- If cs is added to liquid, make sure to rinse out the cs container with the liquid being consumed. This ensures the entire dose is consumed, and no residue is left inside the cs container.

# NUTRITION

## DIET RECOMMENDATIONS BY GSD TYPE

### Type I

- Restrict simple sugars which are: Glucose, Galactose (dairy sugar), Lactose (galactose + glucose), Fructose (fruit sugar) and Sucrose (fructose + glucose)
- Exclude Sorbitol (sugar alcohol turns into fructose in body)
- Limit sugars to less than 5-10 grams per meal
- Limit Fructose + Galactose to less than 2.5 grams per meal
- Multivitamin, Iron, Calcium and Vitamin D supplementation is very important

### Type 0, VI, and IX

- Consume 2-3g/kg/d protein (meats, dairy & eggs) per day
- Include complex carbs (breads, rice, pasta, cereals, beans)
- Exclude sucrose and/or high fructose corn syrup; Examples of simple sugars are cookies, cakes, pies, doughnuts, and ice cream, etc.
- Limit simple sugars to less than 5-10 grams per meal

### Type III

- Consume 3-4g/kg/d protein (meats, dairy & eggs) per day
- Use protein supplements such as Unjury or EAS
- Lower carbohydrate diet
- Exclude sucrose and/or high fructose corn syrup; Examples of simple sugars are cookies, cakes, pies, doughnuts, and ice cream, etc.
- Limit simple sugars to less than 5-10 grams per meal

## MISCELLANEOUS

- **MILK:** Alternate kinds of milk include rice milk, almond milk, muscle milk and soy milk (plain, unsweetened and enriched/fortified)
- **FLAVORINGS:** Sugar free flavorings are good option. Read the ingredients and compare to what is allowed for the type of GSD.
- **DRINKS:** Avoid sports drinks, regular sodas, juices, flavored water and sweetened milk drinks
- **LOW SUGARS:** Always have glucose tablets, smarties, pixi-stix or GlucoBurst in the car, in your purse, pocket and/or emergency kit.

## VITAMINS

### CALCIUM SUPPLEMENT SUGGESTIONS

- UpCal D (powder) – Global Health Products
- Cal-Quick (liquid) – Twin Lab
- Calci-Mix (powdered capsule) — Watson Pharmaceuticals
- CitraCal (tablet) or any type of calcium citrate
- Tums (tablet) – available in sugar-free
- Calcium Carbonate

### MULTIVITAMIN SUGGESTIONS

- One-A-Day (sugar-free, children's and adult varieties are available) or generic equivalent
- Flintstone's Complete (sugar-free is available)
- Natrol for Children (liquid, non-sucrose in CVS & Walgreens)
- Poly-vi-sol (liquid for infants & Children)
- Centrum or generic equivalent (liquid form at Walmart)
- Reviva (sucralose, maltodextrin in Sam's Club)

### IMPORTANT NOTES ABOUT TAKING MULTIVITAMINS AND CALCIUM

- Better absorption of the multivitamin occurs when taken with food.
- Do not take more than 500 mg calcium at one time. If more than 500 mg calcium supplementation is needed daily, separate each dose, and take with a meal.
- It is **not** recommended to take the multivitamin at the same time as the calcium supplement.
- It is also **not** recommended to take the calcium supplement at the same time as an iron supplement, as iron inhibits the absorption of calcium, causing less to be absorbed.

## ORAL HYGIENE

Good oral hygiene is always important. Make sure teeth are brushed regularly and before bedtime. Also, after middle of the night feeds, rinsing with water to clean the mouth is recommended.

### WHEN TO CONTACT YOUR GSD DIETITIAN

- To verify or get a list of foods, allowed/not allowed, according to GSD Type
- Weight is of concern
- Child is not eating, or suggestions for a picky eater
- Assistance with any diet questions or difficulties

# SUGARS

## SUGARS NOT ALLOWED

- Agave Nectar/Syrup
- Brown Sugar
- Confectioners Sugar
- Fructose (natural sugar in fruit)
- Galactose (component of lactose)
- High Fructose Corn Syrup
- Honey
- Invert Sugar
- Isolalt
- Lactose (sugar found in milk)
- Maple Syrup
- Molasses
- Powdered Sugar
- Raw Sugar
- Sorghum
- Sorbitol (sugar alcohol)
- Sucrose (common table sugar)
- Sugar Beets

## SUGARS ALLOWED

### **SUGAR**

- Barley Syrup
- Brown Rice Syrup
- Dextrin
- Dextrose
- Glucose
- Maltose
- Maltodextrin
- Pure corn syrup
- Tapioca Syrup

### **SUGAR ALCOHOL**

- Erythritol
- Manitol
- Xylitol

### **SWEETENERS**


- Aspartame (NutraSweet, Equal)
- Acesulfame K (Sunett, Sweet One)
- Saccharin (Sweet'N Low, SugarTwin)
- Stevia
- Sucralose (Splenda)
- Truvia

**Keep fructose + galactose less than 2.5 grams per meal**  
**Keep sugars less than 5-10 grams per meal**

## **Nutrition Facts**

Serving Size 100 grams (100 grams)

### **Amount Per Serving**

<b>Calories</b> 15	<b>Calories from Fat</b> 1
<b>% Daily Value*</b>	
<b>Total Fat</b> 0g	0%
Saturated Fat 0g	0%
Trans Fat	
<b>Cholesterol</b> 0mg	0%
<b>Sodium</b> 2mg	0%
<b>Total Carbohydrate</b> 4g	1%
Dietary Fiber 0g	2%
Sugars 2g	
<b>Protein</b> 1g	
Vitamin A 2%	Vitamin C 5%
Calcium 2%	Iron 2%

\*Percent Daily Values are based on a 2,000 calorie diet.  
Your daily values may be higher or lower depending on your calorie needs.



## **SURGERY LETTERS**

Many surgeons do not have enough information to safely handle surgery for a patient with GSD. It is vital that your surgeon understand that **the GSD patient cannot fast** prior to the surgery, and understand how to manage the GSD patient before, during and after surgery.

Please contact our office well in advance of any scheduled surgery, to get a surgery letter. It is also appropriate for the surgeon and Dr. Weinstein to communicate prior to the surgery.

## **LABS AND ULTRASOUNDS**

Dr. Weinstein's discharge summary, includes how frequently the patient will need to have lab work and ultrasounds.

### **ULTRASOUND**

If your ultrasound is every 12 months, you may have it done during your visit with Dr. Weinstein (if permitted by your insurance)

### **LABS**

Typically labs are done more than once a year. If you do not receive a lab slip, at the recommended time, please contact our office.

## **SCHEDULING**

- As the number of Dr. Weinstein's patients grow, the farther out we are booked. Please do not wait to make your follow up appointment.
- We cannot always accommodate appointments around school calendars.
- At times we will contact patients to see if they are interested in trading appointments to help another patient.
- You may wish to contact our office prior to making travel arrangements.

### **CANCELLATIONS**

Dr. Weinstein has many speaking engagements, and does not always know these dates well in advance. Please be assured that he will not ask to move an appointment, unless he feels the speaking engagement is beneficial to the world wide GSD community, and feels the health of your patient will not be compromised.

## **SUPPLIES AND EQUIPMENT**

**SCALE:** Purchase a scale that weighs to the tenth of a gram (0.1g). Digital pocket or jewelry gram scales can be found online for as little as \$15.00.

**ORALSYRINGES:** Syringes from medicines can be washed and used for children learning to drink cornstarch. Once they are able to suck the cornstarch easily from the syringe you can switch to straws.

**FLEXI STRAWS:** Straws with a wider diameter are best for night time cornstarch.

**CUPS WITH LIDS:** This combo is helpful to mix cornstarch when no spoons are available. Many choices are available, such as specimen cups or various plastic storage containers.

**WATCHES:** Many varieties of multi-alarm watches are available including those that vibrate. The silent/vibrating watch causes less classroom distraction.

**ALARM CLOCKS:** Alarm clocks are encouraged since keeping to the doctor's cornstarch schedule is very important. If you tend to sleep through alarms, it is beneficial to set more than one alarm.

**PHONE ALERT SERVICE:** There are services available to call at a certain time and alert emergency personnel if no one answers the call. This option is especially useful for those heading to college or venturing out on their own.

**MEDIC ALERT:** The medic alert should have the following information:

- Glycogen Storage Disease (type)
- Severe Hypoglycemia
- No glucagon; D10 only

Add additional information as space permits, such as allergies

# TRAVEL

## TRAVEL LETTER

Dr. Weinstein can provide a letter to assist in carrying GSD supplies on airplanes. A travel letter is automatically provided before you travel for your appointment with Dr. Weinstein. Please contact our office if you need a travel letter.

## AIR TRAVEL

- Bring a current doctor's letter describing the need for cornstarch and liquid as a medication for GSD.
- If the liquid is not a formula, it's often easier not to bring it with you through security but rather purchase the liquid once you have passed through security.
- Doses can be pre-measured but it is recommended to bring an original container also. It doesn't have to be opened.
- Pack the doctor's letter with the cornstarch and place on the belt for screening, when going through security.
- Always carry enough supplies on board, in the possible event your stowed luggage is delayed.

# SCHOOL

## LUNCH BOXES

Require your child and school to bring/send home all left over food in the lunch box. This will allow you to see exactly what is eaten and if adjustments need to be made.

## SNACK BOX

Fill a plastic shoe box with extra snacks that your child can have. If the class is having a special treat that your child can't have, then they won't feel left out, and can have something from their snack box.

## TESTING KITS FOR SCHOOL

- It is recommended to keep one kit with the nurse and one kit in the classroom, if possible. Make sure your child is allowed to carry testing kit supplies and rescue supplies on their person, such as in their backpack
- Testing kits can be stored inside a plastic shoe box, small tackle box, small crafting box, etc.
  - Glucose meter, ketone meter and/or lactate meter
  - Glucose strips, ketone strips and/or lactate strips
  - Lancets
  - Alcohol wipes
  - Band-aids
  - Pocket tissue pack
  - Sandwich bag filled with latex gloves and labeled latex or latex free gloves
  - Small size hand sanitizer
  - Pen and log book
  - 1 box glucose tablets, 2 GlucoBurst gel packs, sandwich bag labeled **Emergency Dextrose Candy** with pixie sticks or Smarties—make sure they are made of dextrose
  - Unopened spare meter batteries (size 2032) for each meter in kit
  - Rx from the doctor can be taped to the inside lid stating that your child can have test strips, lancets, cornstarch, glucose at school
  - Copy of school orders from doctor
  - Copy of Emergency Letter

# SCHOOL

## SCHOOL LETTERS

Schools often require a letter from the doctor to be on file for students with GSD.

Please contact our office to request a school letter.

The following information is needed before a school letter can be prepared:

- Fax number and name of contact to receive the letter
- Patient name
- Patient date of birth
- Current eating and cornstarch schedule, along with cs doses
- Mode of transportation to and from school (walk, bus, etc)
- School day schedule
  - Wake up time
  - Breakfast time
  - Time school begins
  - Snack times
  - Lunch time
  - Recess/gym
  - Time school ends
  - Time returns home
- Does student attend an after school program?
- Do you prefer you child's glucose to be monitored regularly at school? If so, at what times?
- Will your child need to carry any supplies or emergency rescue items on their person while at school? If so, please list all items.
- Are there any special requests you would like included in the school letter?

There are also specific situations, such as gym class, where a letter is required. Please send our office an email with the following information:

- Fax number and name of contact to receive the letter
- Patient Name
- Class or activity
- Any details that would help explain why an exception is needed

# SCHOOL

## SCHOOL 504 PLANS/IEP PLANS

Each state has its own forms and some have different plans as well. Section 504 of the Rehabilitation Act of 1973, gives rights under the federal law to students with disabilities.

## 504 vs IEP (Individual Education Plan)

- If a minor has glycogen storage disease, consider a 504 plan.
- However, if absences are frequent, there are additional medical/learning difficulties, or care is more extensive, you may want to consider an IEP.

## NO MATTER WHICH PLAN, KEEP THESE THINGS IN MIND

- Doctor's orders need to be followed during school
- Request for student to have access to testing supplies as well as ability to carry on person
- Additional time/instruction for time missed due to medical needs
- Planning around cornstarch/snack administration
- Breaks from physical activity as needed without consequence
- Additional time to be given to complete tasks
- Make up work due to absences
- Excused absences for medical purposes
- Breaks allowed as needed for blood testing, bathroom usage, and/or cornstarch/snack at all times, even during exams
- Access to snack/cornstarch
- Adult escort to the nurse/clinic when not feeling well or questionable (irritable, tired, moody, stomach ache, etc.)
- Allowed to test her/himself if able to but school must have someone willing to test as well at all times
- When behavior is questionable check blood first
- Access to front of lunch line to make sure meal is on time
- Cornstarch administration as on medical plan per doctor
- Blood monitoring provided as on medical plan per doctor
- Ability to keep supplies with student at all times
- Monitoring of student closely on field trips
- Inservicing teacher(s) on child's disability

Continued

## SCHOOL

Continued

- Physical Education should be followed per medical plan per doctor
- Allow additional time for lunch/snacks if needed, as well as monitoring that they are consumed
- Contact parents if suspected illness, questionable blood values/results, symptomatic complaints, out of the ordinary behavior
- Contact parents regarding planned snacks/activities so they can send in alternative snacks/plans
- Elevator access if necessary
- Double set of books
- Modified emergency drill route with a buddy
- Longer time to travel between classes
- Central locker location/height for easier accessibility

## SPORTS

Be sure to check with your doctor to determine if sport/physical activity is medically acceptable. Blood values should be taken prior to and after any physical activities, to determine if a snack or additional cornstarch should be provided.

- Any sport that could potentially hurt/damage the liver with direct contact, should be carefully considered with your doctor
- Additional steps may be necessary to stay safe (ie: a flak jacket in football)
- Swimming utilizes a lot of energy for both physical activity and to keep the body warm. It is often the most difficult to maintain blood values during swimming, for those with GSD. Remember to test prior, **during**, and after swim times and adjust with cornstarch as necessary

## **COLLEGE**

This section is written for the student living in a dorm. Colleges are different, so some information may not apply. Contact our office, if the college will not help you with what you need.

### **BE YOUR OWN ADVOCATE**

The student has rights under the American with Disabilities Act, since GSD is a medical disability. The student needs to feel comfortable standing up for these rights. Each college has an office for students with disabilities.

### **BEFORE SCHOOL BEGINS**

- Visit the campus
- Determine the best housing and cafeteria option
- Contact food services to ensure they will have the needed foods
- Visit the campus disabilities office and meet with the department head
- Determine which hospital will be used in the event of a medical emergency; provide information on GSD to the ER
- Hand out copies of your emergency letter to the infirmary or health office

### **CHOOSING A DORM & ROOMMATES**

- Consider the distance to the cafeteria (do not want significant exertions before breakfast)
- Choose/request roommates who can handle multiple alarm clocks and are willing to assist with medical emergencies
- Consider the number of floors up, if the use of stairs is required

### **EATING CHOICES**

- Quick access to room refrigerator, kitchen, and cafeteria
- A room microwave is convenient for pasta, oatmeal, etc
- Make a list of good snacks to be kept on hand in room
- Keep glucose tablets/smarties/pixi stix in room at all times

### **CLASSES**

Plan a class schedule that allows:

- Breaks to be able to keep therapy schedule
- Manageable distance between classes
- Enough time to change classes



# COLLEGE

## ALARMS

- There are different styles of alarms for deep sleepers
  - Sound Alarm pillow
  - Alarm that has outlet for iPod
  - Alarms that count down (can be easier to use than clocks that need to be reset)
- Use multiple alarms

## EMERGENCY LETTER

- Post a copy above the student's bed along with steps for handling an emergency (see page 3)
- Give a copy to the health services department, campus security, the RA and the RD
- Keep a copy in carry bag
- Keep a copy in car and wallet

## MEASURING OUT CORNSTARCH

- If using reusable containers, have a small wash pan, dish soap and bottle brush for cleaning
- Ziplocks are a good options since they do not have to be washed or carried back to the room for reuse. The corner can be ripped to drink directly from the bag
- 8 oz. containers are good for drinking overnight doses

## CARRY BAG

ALWAYS carry a stocked supply bag. Plans can change at the last minute, so be prepared, even if leaving the room for just a few minutes. Stock enough supplies for one day. Include:

- Copy of emergency letter (& copy travel letter since carrying cs)
- Cornstarch (rotate cs to keep fresh)
- Glucose tablets
- Glucose meter
- Snacks
- Bottled water
- Cornstarch in container (large enough to mix in)

## WALLET

- Keep a list of medications, dosing, emergency contacts, etc.

## FLASH DRIVE

- Carry a flash drive with emergency letter, travel letter, etc.

# **INSURANCE**

## **First Time Visits and Return Visits**

### **THE TOPIC NO ONE LIKES**

How your hospital and physician's fees are paid, is determined by your insurance policy. Your insurance policy is a contract between you (or your employer) and your insurance company. The hospital provides a service and in return is paid for the service. It is the hospital Admissions Representative's responsibility to collect all co-pays or deductibles that are due, per your policy.

### **YOUR FINANCIAL RESPONSIBILITY**

"The contract, or **policy**, spells out what the insurance company will pay for and how much of the bill you will have to pay. For example, the policy may cover an office visit, but you may have to pay a \$20 **co-payment**. Or, the policy may not cover anything until you've paid an agreed upon amount out of your pocket, which is known as a **deductible**. These deductibles and co-payments, along with any other non reimbursable expense you may pay is referred to as an **out-of-pocket-expense**. Other policies may have **co-insurance**, which is a percentage of the bill that you're required to pay, which may be in addition to your deductible and co-payment. Often, the total amount of co-insurance you have to pay in a given policy is capped by the policy's **maximum**. The policy will also state the amount you have to pay each month for the coverage, known as the **premium**, and the total amount the insurance company will pay out for the life of the policy, which is commonly referred to as a **lifetime maximum**." (How Health Insurance Works; by Lee Ann Obringer and Melissa Jeffries/ <http://health.howstuffworks.com/medicine/healthcare/insurance/health-insurance.htm>)

## **BILLS**

- **Shands at the University of Florida (SUF)** is a teaching hospital. The hospital fees are billed separately from the physician's fees.
- **University of Florida Physician's** fees are for Dr. Weinstein, physicians who read tests (ultrasound, cardiac echo, etc), and physicians who have called in for a specialty consult (cardiologist, etc).
- All fees are hospital fees except the physician fees.
- If you have questions regarding your bill:
  - Contact the number on the bill
  - Request and itemized bill, from the billing office
  - Contact our office

# **COVERAGE AND AUTHORIZATION**

## **First Time Visits and Return Visits**

### **TYPES OF COVERAGE**

1. Self Pay
2. In Network
3. Out of Network
4. Out of state (outside Florida) Medicaid
5. Florida Medicaid

### **1. SELF PAY**

Our office will discuss the type of visit and services, with the patient/parent prior to the appointment. Our office prepares and estimate, based on prior patient bills. The estimate is given to the Admissions management to see if it qualifies for a cash pay discount..

Then the estimate is provided to the patient/parent. The payment of the estimate is due, in full, at the time of the admit. Two separate payments are made, one for the hospital and one for the physicians. All common methods of payment are acceptable, except foreign currency. Overpayment will be refunded. Underpayment will be billed to the patient.

### **2. IN NETWORK**

In network means that SUF already has a contact with the insurance company. Admissions will call your insurance company for the following:

#### **Coverage:**

- The policy is verified to make sure it is active (in effect) at the time of your appointment
- The benefits are verified to determine what the insurance company will cover and what is the patient's responsibility

#### **Referral:**

- Admissions will check to see if a referral is needed from your primary care physician

#### **Authorization:**

- Admissions will check to see if authorization is required. If no authorization is required, no further action is needed
- If an authorization is required, medical records are given to support why the hospital stay is necessary (This is one reason why we need good records from new patients)
- If an authorization is required, but there is no authorization in place at the time of the visit, the insurance pays nothing

# COVERAGE AND AUTHORIZATION

## 3. OUT OF NETWORK

Out of Network means that Shands at the University of Florida (SUF) does not have a contract with the insurance company.

Admissions follows the same steps as In Network, along with the additional steps listed below.

### **PSA (Prior Service Agreement)**

- Admissions notifies the SUF Managed Care Department that a PSA is needed.
- Managed Care contacts the legal department of your insurance company to work out an agreement for this one time visit.
  - Without the PSA, the insurance company decides what amount it will pay and often it is a very low percentage of the billed amount.
  - The contract is terms both sides agree on.

### **Authorization**

- Some out of network policies will allow their insured to go out of network, but the patient will have to pay a very high co-pay or deductible.
- Admissions contacts the insurance company to try and get an in network authorization approved.

## 4. Out of State Medicaid

Out of state Medicaid is handled differently. Dr. Weinstein is the only physician at SUF that schedules non emergency patients who have out of state Medicaid.

- Our office notifies the SUF credentialing department of what state we have a Medicaid patient coming from
- If we are not already credentialed, up to four months is needed to get the credentialing (contract).
- Closer to the time of the appointment, Admissions will verify benefits and obtain an authorization, like they do with commercial insurance.
- **These authorizations are difficult to get**, and possibly will not get approved. Please provide information regarding any contacts you have with Medicaid, such as case managers, and work with you local provider to get their assistance in getting the authorization.

## 5. FLORIDA MEDICAID

Admissions verifies the coverage and requests an authorization. Typically this coverage does not present many problems.

## **COVERAGE AND AUTHORIZATION**

### **PRIOR TO YOUR VISIT**

- If you are a new patient, our office needs your insurance information as soon as possible.
- You are responsible for notifying our office of any insurance changes, as soon as the change occurs.
- If you are a new patient and have out of network insurance, check with your local doctor's office to see if they will help get the authorization.
- Notify our office if you have a case manager or someone who is helpful with getting your insurance to cover services.

### **REASONS WHY INSURANCE MAY NOT PAY**

- If you have a HMO, etc, the insurance company requires you to see an in network physician
- The insurance company feels there are specialists in your area that can give the same care
- The insurance company feels you are receiving adequate care from your local physician
- Your local physician will not give a referral for the patient to see Dr. Weinstein
- An authorization was required, but not approved *prior to the visit*
- If not contracted, there was an authorization, but no PSA was signed prior to the visit

### **INSURANCE AUTHORIZATION INFORMATION**

- Typical stay for new patients: 2 night In Patient stay or 48 hour Observation stay
- Typical stay for returning patients: 23 hour Observation Stay, (many insurances do not require an authorization for an observation stay); please check with Dr. Weinstein if you feel your patient needs a 2 night stay;
- Please contact our office for codes, tax ID's etc. if you wish to work on the authorization

### **ASSISTANCE IN FINDING COVERAGE**

With the new federal law, Affordable Care Act, there are more options available for patients who have difficulty finding coverage due to a preexisting condition. The website, [www.healthcare.gov](http://www.healthcare.gov) provides a great deal of information to help find coverage for many different situations, including Pre-Existing Condition Insurance.

# FUN

## USES FOR CORNSTARCH

1. Face paint
2. Finger paint
3. Substitute for paste (food coloring can be added)
4. Roach pesticide, when mixed with Plaster of Paris
5. Eliminate stains on leather or silk
6. Remove grease splatters from walls
7. Soak up furniture polish residue
8. Freshen carpets
9. Polish silver by mixing with water to make a paste
10. Window cleaner
11. Prevent and eliminate mildew on books
12. Substitute for talcum powder
13. Treatment for diaper rash
14. Itch relief (mix with water to make a paste)
15. Sunburn relief
16. Dry shampoo for the family canine, stuffed animals, and people
17. Freshener for shoes and showers
18. Emergency substitute for spray starch
19. Untangle hair, string, yarn, etc
20. Cooking
21. GSD treatment

## SCIENCE FUN

What do quicksand, sound, states of matter, oobleck, monsters, slime, suspension, non-Newtonian fluid, isotropy, thixotropy, ooze, invisible ink, dilatants behavior and walking on water have in common?

These relate to some of the messy fun that can be had with experiments using cornstarch! There are many experiments and YouTube videos on line.

# **FUN**

## **DISNEY GUEST ASSISTANCE CARD**

The GAC helps special needs guests gain access to Disney attractions that they would otherwise not be able to see. The GAS is not a convenience, it is a tool for access. Go to Guest Relations, at the entrance to the park, to request a GAC. A doctor's letter is not required, however, we are happy to provide a letter. Contact our office for more details and for a letter.

## **COME BACK LINES**

- No sugar please; I'm sweet enough.
- I have GSD ; it stands for Got Super Determination.
- I was born with it. What's your excuse?

## **COME BACK LINES IN THE CHECK OUT LINE**

Cashiers often ask why are you buying so much cornstarch

- Glycogen storage disease medication
- Arts and crafts project
- Science experiment
- I make lots of gravy
- Home remedy for roaches

**The information given in this booklet is intended  
to help our families who live with GSD.**

**This information does not override  
or come before the information you receive  
from your professional health care providers.**

**Please check with your primary team  
to review specific recommendations.**

**The University of Florida GSD Program,  
dedicates this book  
to the parents & patients  
who live GSD 24 hours a day.**

**We are inspired by your courage to face each day  
and your work toward a better tomorrow.**

**We give a special thanks to the GSD families  
who shared information for this booklet.**