

WORKSHEETS

Childhood Nephrotic Syndrome

Developed by

Pediatric Nephrology Program
British Columbia Children's Hospital
British Columbia Provincial Renal Agency
Vancouver, British Columbia, Canada

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When and how to contact us

If you think your child needs to be seen or if they are having problems we recommend that you first try to contact your family doctor or pediatrician. If you are not able to reach your doctor, you can contact the Renal Program at BC Children's Hospital.

During business hours, please call **604 875 2272** and we will connect you with one of the team members.

Outside business hours, please call the hospital switchboard at **604 875 2345** and ask for the kidney doctor (nephrologist) on call.

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Introduction

Children with nephrotic syndrome require shared and ongoing care. Families, family doctors, pediatricians, and kidney specialists play an equally important role. Managing this condition goes beyond doctors' offices and hospital clinics. In fact, most of the day-to-day monitoring and treatment is done right at home.

To help families of a child with nephrotic syndrome we have developed the *Childhood Nephrotic Syndrome Parent Handbook* and accompanying *Worksheets*. The handbook provides general information about the condition and its treatments. The worksheets are practical, easy-to-use, and can be filled in at home. The nephrotic syndrome worksheets are used to keep track of prednisone dosing, urine dipstick results, relapses, and possible side effects or complications. The food intake records will be completed at 4-weeks and 12-months after diagnosis to assess your child's usual intake of sodium, calcium, and vitamin D.

You should update your child's *Worksheets* regularly and bring it to every clinic visit. Doing this will give your doctors a better picture of your child's course. It will also help them to decide on the best treatment.




Starting prednisone for initial diagnosis

Once your child is diagnosed with nephrotic syndrome, they will need to start prednisone. You will get a prednisone schedule for initial presentation to help you manage your child's prednisone dosing at home (*Figure 1*).

Your prednisone schedule will outline:

1. How much prednisone to give for each dose
2. When to start and stop each dose
3. How many pills (or milliliters [mL] of liquid) to take for each dose
4. How much sodium your child can have while they are on prednisone
5. How much fluid your child can have until they are in remission
6. When you should see your doctor for a follow-up visit over the next year



BC Children's Hospital
Division of Pediatric Nephrology

**NEPHROTIC SYNDROME PREDNISONE SCHEDULE
(INITIAL PRESENTATION)**

Date* (25Dec2015): _____ (*Please enter exactly as shown)

Gender: _____

Weight (kg): _____

Height (cm): _____

Body Surface Area (m²): _____

Formulation: _____

ROUNDED DOSE (mg)	DURATION (weeks)	# of PILLS (50mg)	# of PILLS (5mg)	# of mLs (5 mg/mL)	# of mLs (1 mg/mL)	START DATE* (25Dec2015)	END DATE (25Dec2015)
daily	6 weeks						
alternate day	6 weeks						
STOP							

Recommended maximum sodium and fluid intake

Sodium (mg): _____ (daily while on prednisone)

Fluid (ml): _____ (daily until remission)

Target follow-up dates (during the first year)

1 week: _____ 6 month: _____

4 week: _____ 9 month: _____

12 week: _____ 12 month: _____

Attending Physician: _____


Physician Name: _____

Physician Signature: _____

Figure 1

Re-starting prednisone for relapses

When your child has a relapse, they will usually need to re-start prednisone treatment. You may get a prednisone schedule for relapse to help you manage your child's relapse prednisone dosing at home (Figure 2). The prednisone schedule for relapse is very similar to the one for initial presentation, except shorter. This is because the treatment of relapses is shorter than the initial treatment.



BC Children's Hospital
Division of Pediatric Nephrology

**NEPHROTIC SYNDROME PREDNISON SCHEDULE
(RELAPSE)**

Date* (25Dec2015): _____ (*Please enter exactly as shown)

Gender: _____

Weight (kg): _____

Height (cm): _____

Body Surface Area (m²): _____

Formulation: _____

ROUNDED DOSE (mg)	DURATION (weeks)	# of PILLS (50mg)	# of PILLS (5mg)	# of mLs (5 mg/mL)	# of mLs (1 mg/mL)	START DATE* (25Dec2015)	END DATE* (25Dec2015)
daily	Until remission						
alternate day	2 weeks						
STOP							

Recommended maximum sodium and fluid intake

Sodium (mg): _____ (daily while on prednisone)

Fluid (ml): _____ (daily until remission)

Attending Physician: _____

Physician Name: _____

Physician Signature: _____

Figure 2

Using the worksheets

Once your child has started prednisone treatment, please keep a daily record of all their urine dipstick results, prednisone doses, weight, and any other health information, such as new illnesses (colds, diarrhea, flu), side effects (heartburn, stomach pain), or other medications.

Prednisone dose

Write down how much your child is taking in milligrams (mg).

This should be done:

- Every day you give it to your child
- Whenever you change the dose

Weight

Write down how much your child weighs in kilograms (kg) or pounds (lb).

Make sure you specify whether you are measuring in kilograms or pounds.

This should be done:

- First thing in the morning
- Every day until remission
- Once a month otherwise

MONTH/YEAR	URINE RESULTS	PREDNISONE DOSE	WEIGHT	COMMENTS
April 2016				
1	4+	60mg	50kg	Using 5mg tablet; a little swollen; started taking 1,000 IU vitamin D and 500 mg calcium
2	3+	60mg	50kg	Using 5mg tablet
3	2+	60mg	50kg	
4	2+	60mg	50kg	Difficulty swallowing tablet. Called doctor.
5	1+	60mg	50kg	Started 5mg/mL prednisone liquid (per Doctor)
6	Trace	60mg	49kg	
7	Negative	60mg	49kg	
8	Negative	60mg	48kg	Swelling improving. Started on Zantac for heartburn.

Worksheet 1 sample

Urine results

Write down the results from your child's first morning urine dipstick test.

Make sure that your child's urine dipstick results are recorded as: negative, trace, 1+, 2+, 3+, or 4+. DO NOT record the g/L or mg/dL number values on the dipstick container itself (see *Figure 3* on next page).

Comments

Write down any other health information about your child. (Such as, other medications or supplements, side effects and any new illnesses.)

Urine protein testing at home

What is a urine dipstick?

A urine dipstick is a valuable tool for diagnosing and monitoring various types of kidney conditions including nephrotic syndrome.

There are many different brands of dipsticks available. Different brands measure different things in the urine, such as protein, blood, glucose, or white blood cells. For children with nephrotic syndrome, we are only interested in how much protein is in the urine. Albustix® measures only protein and are therefore recommended for home use.

How does a urine dipstick work?

Dipsticks work by measuring how much protein is in the urine. Dipping the test strips into a freshly collected urine sample causes the color of the strip to change. The more protein present, the more the color changes.

How do I use a urine dipstick?

1. Check the expiry date of the test strips on the bottle label. Do not use expired strips.
2. Make sure they are stored as directed. Tightly close the bottle cap after each use. Keep the bottle at room temperature and away from sunlight.

3. First morning urine is best. Always test fresh urine collected in a clean dry container or by squeezing cotton balls from a wet diaper for children who are not toilet trained.
4. Dip the whole test area and remove the strip immediately.
5. Remove excess urine by running the edge of the strip against the rim of the urine container.
6. After 60 seconds compare the test area closely with the color chart on the bottle label (see *Figure 3*).
7. Record the results in your worksheets as negative, trace, 1+, 2+, 3+, 4+ and not the number values on the dipstick container recorded in g/L or mg/dL.

Write down the protein results from your child's first morning urine dipstick test in your worksheets.

Urine dipstick testing should be done:

- Every day while your child is on daily prednisone
- On the same day that your child takes their alternate day prednisone
- Every day while your child is having a relapse and waiting to respond to treatment
- Every day whenever your child is unwell or looking swollen



Record this green shade as 4+ in your child's worksheet.

(Note: The 1+, 2+, 3+, 4+ indicators in this photo are not on the actual label.)

Dipstick turned green after 60 seconds.

Figure 3. This is an example of a urine dipstick test. The dipstick at the bottom of the picture has turned a shade of green after 60 seconds. The green shade in this picture would be recorded in your child's Nephrotic Syndrome Worksheet as 4+, NOT ≥ 2000 or ≥ 20 as indicated on the bottle. The + indicators (1+ to 4+) do not actually appear on the bottle.

Urine protein testing at home (continued)

Helpful hints

- 1. Write down EVERYTHING:** Small details help. The more you can tell your doctor the better.
- 2. Do it right away:** Don't depend on your memory at the end of the day. Record doses and urine results as they are taken during the day. Keeping the worksheets up-to-date will enable your doctors to better track your child's course and treatment response.
- 3. Be specific:** More details help ensure accuracy. Make sure you record urine dipstick results as: negative, trace, 1+, 2+, 3+, or 4+. DO NOT record the g/L or mg/dL number values on the dipstick container itself. Also, make sure you record whether you are taking your child's weight in pounds or kilograms.
- 4. Bring them to clinic:** Your doctor will review these worksheets every time you come to clinic. Even if you have not been using your worksheets regularly, it is still important that you bring you them to each visit. A little bit of information is still better than none.
- 5. Ask questions:** If you have any questions about how to fill in these worksheets, just ask. Your doctors are always there to help!

Nephrotic syndrome worksheet

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When your child has finished 1 month of prednisone, remember to complete a 4 week food record and bring your *Worksheets* to your next clinic visit for your doctor to review.

Nephrotic syndrome worksheet

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Using the food intake record worksheet

When your child has been on prednisone for 4 weeks, please provide a 3-day record of all food and fluids taken to assess your child's usual intake of sodium, calcium, and vitamin D. Another 3-day food record will be repeated at 12 months after diagnosis.

Time?

Write down the time of day the food or drink was taken.

How much?

Write down how much your child ate. Estimate the size (2" X 1" X 1"), the volume (1/2 cup or 125 mL), the weight (2 oz), and/or the number of items (12) of the food or drink.

What food or fluid?

Write down the type of food or drink taken. Provide lots of details:

- regular vs. diet gingerale
- french fries vs. potatoes

Include any extras such as gravy, butter, cream, sugar, and/or ketchup.

TIME	HOW MUCH	WHAT FOOD OR FLUID	WHERE
8:00 am	1 large glass (375 mL)	milk 1%	home
8:00 am	1 bowl (1 1/4 cup)	oatmeal prepared with water	home
SUPPLEMENTS			
1 tablet	vitamin D 400 IU		
1 tablet	multivitamin (e.g. Centrum Junior brand)		

Worksheet 2 sample

Supplements?

At the bottom of each page, write down the type and amount of supplements, vitamins and or minerals that are taken each day.

Where?

Write down where the food or drink was taken:

- home vs. school
- fast food chain vs. restaurant



British Columbia Children's Hospital
4480 Oak Street
Vancouver, BC V6H 3V4
Hospital Switchboard
Tel 604 875 2345
Toll free in BC 1 888 300 3088
Division of Nephrology
Tel 604 875 2272