|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Name of Medication(include all names of the medication on the label) | Medication strength OR concentration  | Dose(clearly mark dose in mg, g, mL, number of tablets, puffs, etc.) | Time given (for example 8 a.m. or 6 p.m.)If medication is only given weekly indicate which day of the week and when it was last given or when it should be given. | Reason the medicine is given.For medication only given on an as needed basis, please indicate why you would give the medication. | Any special instructions or other information you want us to know to guide medication administration?  |
| Apo-Clobazam 10mg | Clobazam 10mg (tablets) OR\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Clobazam liquid 5mg/5ml oral suspension compound | Take **½ tablet** at bedtime\_\_\_\_\_\_\_\_\_\_\_\_Give 10ml (10 mg) at bedtime and in morning | 8pm, 8 am | Khyra has silent seizures according to an EEG, and has recently had a outward seizure. Clobazam is to prevent seizure activity.  | **In tablet form**, the tablet must be cut in half, crushed and mixed with water (60ml) in a syringe, administer through G-tube\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_In oral suspension compound form please refrigerate.  |
| Sulfasalazine | 100mg/ml | Give 5 MLS THREE TIMES DAILY | 12am, 8am, 4pm | To treat colitis and arthritis  | Ordered from the Medicine Shoppe1(306)543-5555 Will deliverKeep refrigerated |
| ~~Compound Zinc~~ | ~~15mg/5ml~~  | ~~Give 5MLS TWICE DAILY~~  | ~~8am, 8pm~~ | ~~Has low zinc levels~~ | Ordered from the Medicine Shoppe1(306)543-5555 Will deliverKeep refrigerated |
| Prevacid FasTab 15mgOR LIQUID (Lansoprazole 3mg.ml suspension compund  | 15mg | Give 1 tablet twice a dayLiquid: 5ml/BID | 8am, 8pm | Reduce stomach acid to prevent lung damage when aspirating | Order from Shoppers 1(306)949-6616 Will deliverDissolve in 60 ml of water in a syringe, give via g-tube. |
| Nasonex AQ Nasal Spray 50UG MOMETASONE FUROATE 50MCG (140 dose)  | 50MCG (140 dose) | Use 2 sprays in each nostril Once daily at bedtime | 8pm | Help with sleep apnea, airway.  | Order from Shoppers1(306)949-6616 Will deliver |
| FLOVENT HFA 125 MCG (120 dose) | 125 MCG (120 dose) | Inhale 1 puff twice a day via aerochamber | 8am, 8pm | Helps with lungs | Order from Shoppers, 1(306)949-6616 Will deliver, count to ten out loud when delivering it (Orange) |
| D-VI-SOL Drop Vitamin D3 | Drops 400 IU per ml | Give 2. 5millilitre(s) once daily | 12am |  | Order from Shoppers1(306)949-6616 Will deliver |
| Clotrimaderm CRM 1% (clotrimazole 1%) |  | PRN | Diaper changes-Bum cream | Helps with redness and bum irritation | Order from Shoppers1(306)949-6616 Will deliver |
| Calcium Liquid 20mg/ml (350ml)(solucal) | 20mg/ml250mg=12.5ml  | 250mg=12.5ml via G-tube  |  4pm | Increase calcium levels | Shoppers |
| Ondansetron oral sol ondansetron HCL (zefron) | 4mg/5ml | Prn 5ml via g-tube | PRN  | Anti-nausea- non-drowsy (used to treat patients in Chemo)  | Shoppers- will be kept in her school bag. |
| Gravol Natural Source | 20mg talbets | PRN crush 2 tablets mixed with 40ml of water given via g-tube every 4 hours 1-3 times a day.  | PRN  | Anti-nausea | Shoppers- will be kept in her school bag. |
|  |  |  |  |  |  |
| ~~Hyderm CRM 1%~~Tara-Clobetasol Oint 0.05% | ~~Hydrocortisone acet 1%~~Clobetasol Propion 0.05% | Apply to red spots twice daily | AM care and before bed | Heals red spots | Pityriasis Rosea is a rash, This new cream has been prescribed by a dermatologist Dr. McKay October 10, 2014  |
| Bio-Oil |  | Apply to dry skin or scars, body and face where needed. | AM care and before bed | Helps keep skin healthy in harsh weather, and helps reduce scars | Non-prescription  |
| Melatonin Fast Dissolving  | 3mg | Give two tablets at 8pm, give one tablet at 2/3 am  | 8pm, 2/3am(when she awakes throughout the night) | Helps increase total sleep and sleep quality | Purchase from Shoppers, not covered. Dissolve in 60 ml of water in a syringe, give via g-tube. |
| Diastat rectal syringe 5mg (Diazepam 5mg/ml) | (Diazepam 5mg/ml) | Insert 5mg dose into rectum with seizure greater than 5 minutes | PRN | Treats a hard to stop seizure | Seizure protocol: administer 2litres O2, or enough to maintain sats, call 911, call parents, administer Diastat after 5 minutes, tell first responder you administered Diastat. Current expiry date: 07/2015. Found in red emergency bag (back pack) ; goes with Khyra everywhere.  |
| Ventolin HFA 100UGSabutamol 100MCG200 dose | Sabutamol 100MCG | Inhale as needed- usually 2 puffs gid prn may even increase to 5 puffs every 4 hours when distressed with lots of secretions. (10 puffs if necessary)  | PRN | If Khyra is not maintaining sats, usually due to a cold, she is given sabutamol, and O2 is given. \*usually during sleep, | Found in red emergency bag (back pack) ; goes with Khyra everywhere. Parents to be notified.  |
| Phosphate Novartis 500mh/ phosphorus 500mg wht/rnd/none | 500mg | Dissolve 1 tablet in 1/3 to ½ cup water and give ~~twice~~ once daily as directed for 6 weeks | 12am, ~~8am~~ |  |  |
| 50ml Calcitriol 0.5mcg/5ml Emulsion Compound | 0.5mcg/5ml | Give 5ml (0.5MCG) once daily as directed | 4am | NOT to be given within two hours of other meds that are minerals. Another form of vitamin D for patients with osteoporosis.  |  |
| Tylenol | 160mg/5mls | 15ml (78lbs) | PRN | Give first to break a fever | Parents to be notified.  |
| Children's Advil | 100mg/5mls | 19ml (78lbs) | PRN | Give second, 30 minutes post Tylenol, to break a fever if it hasn't gone down with administration of Tylenol.  | Follow administration amount based on her weight. Parents to be notified. |
| Oxygen |  | Enough to maintain oxygen saturation levels above 90.  | PRN | Administered when sick with a cold, usually at night to maintain sats, provided in the event of a seizure, provided during sleep if continuous desats due to sleep apnea.  | Parents are to be contact if administering Oxygen.  |
| **NUTRITION/DIET** | **Preparation** | **RATE/DOSE:**  | **Preparation time** |  |  |
| NEOCATE JuniorAmino Acid-Based Formula Hypoallergenic UnflavouredNO FOOD PER MOUTH | 54 scoops of formula with 1700ml warm or cool water (not hot) shake well until powder is dissolved, refrigerate, label time made, good for 24 hours.  | **Rate:** 80ml/hr/24hrs day**Dose:** set at INF on pump**TOTAL: 1920 ml/day** | 6am every day |  | \*CHANGE FEED BOTTLE AT 6:00/6:15am every morning, do not mix old formula with new formula. ALWAYS disconnect at g-tube button if doing a transfer from chair to floor, chair to bed, bed to chair, etc. Dose should be set at INF on pump, check at beginning of your shift.  |
| **FLUSHES** |  | **AMOUNT** | **TIME** |  | Notes:  |
| FLUSHES mixed with meds |  | 120ml 60ml60ml | 2am8am8pm |  | **2am:** Mixed with melatonin to dissolve**8pm:** mix prevacid and melatonin in syringe with 60 ml of water and administer. **8am:** mix prevacid with 60 mls to dissolve, and administer via g-tube.  |
| Post Med flushes |  | 120ml60ml120ml60ml | 12am8am4pm8pm |  | Post: (Sulpha + D-Vi-sol) 12amPost:(Sulpha + zinc) 8amPost: (sulpha)4pmPost: (zinc) 8pm |
| Flushes on their own |  | 60ml 120ml | 4am12pm  |  |  |
| **TOTAL:**  |  | **780ml** |  |  |  |

*\_\_\_\_Terry Burgess\_\_\_\_\_\_\_\_\_\_\_\_\_* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Parent Guardian Name & Signature Date Physician Signature Date

## Khyra Burgess History in event of Emergency: (This information is from memory and is as accurate as my memory:) lol

* Born **November 27th, 2003** Seizures at birth, grade 2 brain bleed, calcifications, hypo plastic lungs (CMV, MRSA) Clobazam for seizure activity.
* Home with 02, was eating by mouth at first, aspiration, pneumonias were ongoing
* **May 10 or 11th 2004** : G-tube
* **June 28th, 2004** tracheotomy and life support (ventilator, suction machine, O2, compressor, HMEs, etc.)
* **July 2004** fundoplication
* Out of the hospital on ventilator in **November, 2004**
* Then apnea condition discovered, so she stayed on it
* **2005/2006 G/J tube**
* **September 11, 2007**, Khyra taken to hospital for Midgut volvulvus was off ventilator, but we still had it. Lost 75% large intestine, but the illosecal valve was intact allowing her to live. She had **Short Bowel Syndrome** following, as her villi needed to grow. Dehydrations followed.
* **September 12, 2007** was the surgery
* **December, 2007:** TPN, got her home just before Christmas?
* **August 2008** tracheotomy removed in Edmonton, put on Bi PAP- pressure both ways, Central and Obstructive apnea condition
* **August 2009** off Tpn
* **November 27**, **2010** discharge after stoma closed at 3pm
* **2010** Femoral osteotomy – She has **metal plate** in hip- right side.
* **Nov. 2011**, going through process to figure out arthritis (rheumatoid arthritis was suspected.)
* **Nov. 2011-Nov.2012** she struggled with arthritis, blood in stools, and dehydration, once a month at least sick for no less than a week.
* **June 2012** blood in stools, dehydration
* **November 2012:** Sulphsalazine for arthritis and colitis, she was on TPN and formula was changed from Vivonex to Neocate Jr. This admission, Dr. Essalah took Khyra off of Bi pap machine.
* **March 2014:** Seizure 2 minutes, EEG in April.
* **She has had 3 seizures in May/June/2014.** She has been doing well since 10ml of clobazam started.
* **Immunization Sept.** 25th, 2014, Hep B, Human Papillomovirus, Meningogoccal Conjugate ACYW-135, Records indicate Varicella (Chickenpox) complete 2005/12/01
* **2014 Dermatologist:** Dr. Roberta M McKay Oct. 10, 2014
* **Flu shot dec.**11, 2014
* **2015, January 7th:** 2 Seizures, 8am Large seizure, then again at hospital. Discovered pnemonia, treated with antibiotics(Ceftin-done), increase in clobazam.
* **January 15th** xray left leg and right arm still sore from seizure- xray came back good
* **January 21st** Right leg was immobile after school during a diaper change- reason unknown. Saturation levels affected 86-89 room air. O2 applied.
* **January 24th** Tylenol Codeine prescribed and started to relieve pain for right leg- itching, constipation present as meds started.
* **January 28th Admission to General** x-ray revealed tibia, smaller bone fractured (ziz zag break) and fibula fractured, larger bone (one bend), both still intact. Full leg cast on right side applied January 29th OR. Discharge on January 29th, 2015. Her bones are **osteoporotic** – very thin 1/3 of a normal bone, and fragile- most bones are white, hers are clearish and pliable- high risk for fractures, lifts should always be two person or using a lift.
* **April 7th, Khyra broke her femur on right leg, was transfered from Wascana to RGH.** Khyra has been diagnosed with osteoporosis. As a result her bones are very fragile. They will not improve. Her phosphate, calcium and vitamin D levels are low. Her thera-thyroid is overworking, this is part of the absorption process (GI system) - it’s overworked because calcium and albumen (protein) are low. She is stable enough to be in the community but will be monitored closely in the community. She is taking calcium supplement, but cannot take Phosphate in the community. This will be given rectally when needed at the doctors after bloodwork is assessed. As a result of the new supplements, and her condition, she is nauseous. When she is nauseous she will gag and retch. This will induce vomiting. Her fundoplication does not work, she will aspirate if she is not sitting up while retching and vomiting. O2 levels are affected by these events. She had borderline bronchial pneumonia, is done treatment, her throat was a bit enflamed, I’ve noticed drooling. \*Note: Zefron is an anti-nausea that won’t cause drowsiness- mostly given to patients undergoing chemo. Discharged april 12,2015 broke femur, has cast.
* **April 24th Dr.** Essalah ordered phosphate due to low levels, and her calcium is high. The two supplements rule each other out, so they are to be given apart from each other. Blood work ordered in two weeks, May 8th. She will be at Wascana so it has been communicated that she will require this done. The rec will be sent. STOP VITAMIN D to days prior to blood work. (May 6th, 7th). An appointment will me made with myself to gather results.
* **April 29th. Dr.** Beggs 9am General: xray done, it will stay on for 3 weeks, at which time the decision to splint or recast will be made.
* **May blood work:** Orders were to discontinue zinc, zinc levels too high, reduce phosphate to 1 tablet a day, and Vitamin d increase to 5 ml.
* **June 4th-** Seen Dr. Beggs bone surgeon, cast off, wascana is going to be contacted to create a brace for transfers only, 3 month term, bones fragile, doc. Says bones require pressure to build strength, catch 22 is that they will break easy with pressure. Blood work done this day. Results to follow. Khyra has been doing well with sats and not being gaggy. Wascana also coming in to home in July to look at lifts and bathroom. Her bed has now been moved to living room to better accommodate lifts.
* **June 18th Khyra has started a new med to help with Vitamin D levels.** This is not not be given with other mineral type drugs, we have set the time for 4am. The compound is almond based so we have been watching for signs of allergies, none to date. It also needs to be shaken well. Her Vitamin D has been reduced to 2.5 ml.

***Diagnosis:*** Short Bowel Syndrome, MR, CP affecting all four limbs- a result of level 2 brain bleed and brain calcifications at birth, Central and obstructive Apnea, G-tube fed, Autistic tendencies, Non-verbal, Arthritis, Colitis, Lung deficiencies, Osteoporotic. -

Blood transfusions: platelette transfers when chronically ill, at least 6?

# Protocols

Khyra has been diagnosed with osteoporosis. As a result her bones are very fragile. They will not improve. Her phosphate, calcium and vitamin D levels are low. Her thera-thyroid is overworking, this is part of the absorption process (GI system) - it’s overworked because calcium and albumen (protein) are low. She is stable enough to be in the community but will be monitored closely in the community. She is taking calcium supplement, ~~but cannot take Phosphate in the community.~~ , and is now taking supplements as required – being monitored with regular blood work. ~~This will be given rectally when needed at the doctors after bloodwork is assessed.~~ As a result of the new supplements, and her condition, she is nauseous. When she is nauseous she will gag and retch. This will induce vomiting. Her fundoplication does not work, she will aspirate if she is not sitting up while retching and vomiting. O2 levels are affected by these events. She had borderline bronchial pneumonia, is done treatment, her throat was a bit enflamed, I’ve noticed drooling. \*Note: Zefron is an anti-nausea that won’t cause drowsiness- mostly given to patients undergoing chemo.

1. **Check O2 every 30 minutes, if below 92, administer oxygen (blow method), until sats are above 92- strive for 98, administer salbutamol (Ventolin) 2-5 puffs.**
2. **If O2 won’t rise, she will need direct oxygen, via mask or cannulas to maintain sats of 92+**
3. **If gagging and retching, administer 2-5 puffs salbutamol (Ventolin), and administer gravol (ginger tablets) with 40ml via g-tube, tablets must be crushed.**
4. **If gagging does not settle in 20 minutes, and or respiratory distress is occurring, call mom to consult on giving zefran- (ondansetron oral solution). We only have 3 doses of this, and needs to be used sparingly.**
5. **Her bones are REALLY REALLY fragile, treat her like a fragile ornament please.**