

1997-98 SESSION
COMMITTEE HEARING
RECORDS

Committee Name:

*Joint Committee for
Review of
Administrative Rules
(JCR-AR)*

Sample:

- Record of Comm. Proceedings
- 97hrAC-EdR_RCP_pt01a
- 97hrAC-EdR_RCP_pt01b
- 97hrAC-EdR_RCP_pt02

➤ Appointments ... Appt

➤

➤ Clearinghouse Rules ... CRule

➤

➤ Committee Hearings ... CH

➤

➤ Committee Reports ... CR

➤

➤ Executive Sessions ... ES

➤

➤ Hearing Records ... HR

➤

➤ Miscellaneous ... Misc

➤ 97hr_JCR-AR_Misc_pt31b_Corr

➤ Record of Comm. Proceedings ... RCP

➤

Really Great People!

Barbara Haase: An incredible resource and home care nurse. She commuted from downtown Milwaukee and later from Madison to take care of Drew while she worked on her Masters Degree. Barbara and her friends built Drew's oxygen carrier truck and his fantasy playhouse. She let Drew shift her stick shift car and included him in her wedding party. She taught Drew to dance in his wheelchair at her wedding reception.

Wilke's Village Pharmacy: Since 1989 they have provided all of Drew's medications, searched through many sources of diapers to find the right size and style for Drew, and even delivered medications from Milwaukee to our home at 2:00 AM!

VCM: Has provided all of Drew's equipment needs and even delivered his pharmacy medications for eight years, always courteous and available. Even available when we had a 15 inch snow fall!

Dr. Kagen: The Neurosurgeon who took personal interest in Drew and patiently answered all of our questions. The tears in his eyes when he told us that the untethering procedure could not be successfully completed because of Arachnoiditis meant more to us than anything he could say.

Waukesha County: For stepping forward with transportation so Drew could attend Happy Times Preschool and for providing the Family Support Program that has helped immensely.

Lincoln National Insurance: For calling when Drew was born to tell us that ALL of Drew's medical bills would be paid in full and also informing us that any home modifications we needed would be paid for!

Dr. Seifert: The eye Doctor whose staff fitted Drew's eyeglasses at school so that he wouldn't have to miss any school.

The Eastern Airlines Silverliners: They provided Drew's trip to see "Santa at the North Pole". They also threw in a rather large stuffed reindeer named Rudolph when Drew refused to release his hug. They also found and paid for a locksmith to unlock our new van which was left running with the keys in it in front of the entrance to the Red Carpet Inn and then brought the things locked in the car to us at the "North Pole".

Dr. Leach: For always being sensitive and responsive to the long list of Drew's needs.

Happy Times Nursery: For providing a first rate caring preschool program.

Kacz at Rehab Design: His wonderful caring, attention to details, long hours, wonderful sense of humor, and even coming to our home to make sure Drew's leg braces fit correctly.

Dr. Rice: Who saved Drew's life in the surgery recovery room after the bagging procedure blew out both of Drew's lungs.

The nameless hospital resident: Who promptly made the decision to do a cut down so Drew could get seizure medication and avoid brain damage when he was in the hospital.

The Country Craftsman: Where Skip and his associates designed and built a marvelous set of bedroom furniture specifically for Drew's needs!

The private airplane pilot: Who after a long day of giving airplane rides for fees, waved for Drew to come along for a free ride!

Motorola: For simply stepping forward and solving a communications problem.

Drew's classmates: Who always include Drew in activities and whose parents support them by bringing them over to play with Drew.

Jean Driscoll: Who not only told us when she was a Milwaukee teenager that a "disability" did not mean "disabled". She has proven it many times since at the Boston Marathon and at the Olympics.

The Kids on the Water program: For introducing Drew to fishing.

The Waukesha YWCA: For a sensitive and supportive summer camp program.

Jean Henning: Who stepped forward to help Drew attend camp, accepted us as part of her family, and included our family on trips to the circus, baseball games, Disney on Ice, to the Zoo, etc.!

UCP: For providing ideas and programs that are both helpful and appropriate!

Kettle Moraine Transport: For excellent service, solving problems, and being there when we needed them!

Vicky Hekkers: As the case manager for our first nursing agency she stepped forward, without any orientation, picked up Drew and his three young brothers from the hospital emergency room and took care of all of their needs so that I could be with my wife during her emergency appendectomy surgery!

Darold Mayer: The cement contractor who built Drew's concrete ramp with reinforcing bars. When it was finished he found an area where water puddled. He tore out the concrete walk and redid the job because it didn't meet his standards!

Wheelchair Recycling Program: A program without which Drew's mobility would be quite restricted!

Marj Matheny (former nurse, afflicted with MS): Who includes Drew in her family's activities and volunteers to take care of Drew when problems arise and we need help.

The Katie Beckett Program: Without it we'd be bankrupt!

The Spina Bifida Center: For not only improving Drew's bladder management but documenting his total developmental progress!

Dr. Splaingard: For his sensitivity, his ideas, and his caring.

Challenge Air Program: The EAA program that allowed Drew to experience the thrill of flying a small plane with the assistance of a "disabled" pilot.

The Disney World attendant at "Mickey's House": After standing in a long line, she closed the door behind our family and said "Drew can take all the time he wants with Mickey, the other children in line can come back, Drew may not have another opportunity".

The many restaurants that have provided special foods and small portions so Drew could be part of the family during the meal.

Marilyn Sherman (former nurse): Who still includes Drew in her family's outings and takes him fishing.

Dr. Glaspy: The intensive care Doctor who met Drew the day he was born and saw him through two months of emergencies, shunt failures, surgeries, infections and other traumas.

Winners on Wheels: A rapidly growing program to help kids in wheelchairs develop skills, become independent and have fun.

Bud Selig: Who sent an autographed team baseball to help make Drew's first trip to see the Brewers especially memorable.

INFORMATION
GIVEN TO FRIENDS
FAMILY & TEACHERS
REGARDING DREW
HIS CARES AND HIS
CONDITION

DREW'S CONDITION - A NONTECHNICAL EXPLANATION

Drew was born with a birth defect called spina bifida. Spina bifida is considered by many medical professionals to be the most common of birth defects. It is caused early in pregnancy when the cells that form the neural tube fail to close. The neural tube is the initial stage of development which becomes the spinal column. Researchers now believe that this is caused by a low level of folic acid during pregnancy; the severity of the defect depends on the size and location of the opening on the spinal column.

Drew's condition can best be described as chronic but stable. He's not fragile and certainly not contagious. His condition does include a number of complications which are not necessarily typical of other people with spina bifida. Drew and a handful of other children with these complex problems are alive today thanks to the exceptional medical people, technologies and services available here in Wisconsin.

Shortly after birth the opening in Drew's spinal column was surgically closed to prevent infection and further damage. A side effect of this procedure is that excessive amounts of spinal fluid are then produced causing the ventricles (sacks of fluid in the brain) to fill excessively. This creates pressure on the brain by pushing it against the bones in the skull. Since the skull's bones are relatively soft at birth the pressure caused his head to increase in size.

In order to prevent the pressure from damaging his brain, a shunt was surgically implanted. The brain shunt is a narrow tube with a valve in the middle. It allows the fluid to drain from the brain's ventricles into his chest cavity where it is absorbed into his body. The procedure leaves a curved scar on his head and a small abdominal scar.

Unfortunately these shunts can become blocked and fail. When this happens the failed shunt must be surgically removed and a new shunt must be placed in another ventricle. Prompt surgical correction is required because the skull becomes harder as Drew gets older. It no longer has the ability to expand in size to reduce the pressure. Now the pressure is fully on the brain. Symptoms such as bulging eyes and headaches are warnings of this condition.

Drew's spina bifida has resulted in damage to the nerves in his lower body. This affects his ability to fully control his legs, his bowel and his bladder functions. These problems are currently being addressed with surgery, physical therapy, braces and electronic stimulation of nerves.

Everyone with spina bifida has a condition called Arnold Chiari where the base of the brain is simply larger than average. A few of these children develop some unusual symptoms which are referred to as Arnold Chiari Syndrome. The symptoms include rapid eye movement, paralysis of the vocal cords and throwing up all food shortly after it's eaten (reflux). Drew's eyesight and hearing are also impaired by this condition.

The symptoms caused by the Arnold Chiari Syndrome have been addressed with a decompression surgery at the back of his head, near his neck, to relieve the pressure. This prevents the symptoms from getting worse but it doesn't eliminate them. To prevent the throat paralysis from becoming life threatening (choking) a plastic trach was surgically implanted in his throat so the airway cannot be blocked.

A device is placed over the trach to allow the air passageway to remain moist and to help the air flow for speaking.

To eliminate the occurrence of reflux (sudden stomach contraction/throwing up), Drew's esophagus has been surgically reduced in diameter. This means he can only eat liquids and soft foods without any texture (no lumps or chunks). To make this easier a "Mickey" (brand name) gastrostomy tube ("G" tube) was surgically implanted in his abdomen to allow liquid feedings directly into his stomach. This allows a larger volume of nutrients to enter his stomach than he would be able to take in by mouth. The feedings are done at two hour intervals to minimize the chance of reflux and stomach irritation.

The nerve problems also result in apnea episodes (breathing stops) while sleeping and difficulty in maintaining sufficient oxygen levels in his blood. The problems become most significant when Drew is fatigued or he does not get enough sleep. At night, leads from an apnea monitor are attached to Drew in order to record his breathing frequency while he breathes supplemental oxygen and is fed using a feeding pump. During the day he breaths oxygen from a portable tank if it's needed.

Today most children with spina bifida, between the ages of 8 and 10, have a surgical procedure performed called untethering. This procedure is to remove the internal adhesions that have formed from the surgical closure of the back after birth. If uncorrected the adhesions may hinder the physical growth of the body.

The untethering procedure was attempted on Drew when he was eight years old. Unfortunately the doctors learned that he has a very rare condition called arachnoiditis (extensive adhesions - like a spider's web). The arachnoiditis condition means that the untethering could not be done without severe risk to Drew. There is no way of addressing this condition with today's medical technology, and its rarity makes this unlikely to change. Its effect on Drew's growth is unknown but it's believed that it is contributing to Drew's frequent headaches. He sometimes wears a neck brace for this reason.

Drew is quite sensitive to sunlight because of his fair skin and red hair. The medications he takes further increase his sensitivity to sunlight - he requires sun block if he is outside for an extended period of time. Serious skin breakdown has resulted when diapers have not been changed promptly. Pressure sores from shoes and braces have caused open wounds deep enough to reach the bone. Some sores have taken as long as four months to heal even with the assistance of a plastic surgeon.

Timely delivery of medications is important to prevent overdosing and underdosing. Some medications are important to prevent dangerous infections. Other medications are required to control stomach irritation and keep it from becoming a serious ulcer. Even a trip to the dentist requires an antibiotic first. Seizures, respiratory congestion and bowel control also require regular doses of medication.

Drew, like many children with spina bifida, is highly allergic to latex (balloons, balls, latex gloves, elastic, tires etc.). Latex must be avoided! Generally his reaction has been a rash and respiratory congestion but in a surgical situation it can be life threatening.

We welcome your questions and appreciate all of your suggestions. No one has all of the answers. The more you understand about Drew the more you will understand about everyone with special needs.

INFORMATION
PACKAGE FOR
NEW NURSES

DREW'S NEWS

IF DREW HAS STOMACH DISCOMFORT IT MAY BE FROM GAS. HE CANNOT RELEASE THE PRESSURE OR VOMIT DUE TO THE ESOPHAGUS RESTRICTION (NISSEN) DONE WHEN THE GASTROSTOMY TUBE WAS SURGICALLY IMPLANTED. THIS CAN BE RESOLVED BY ATTACHING AN EXTENSION TUBE WITH AN EMPTY FEEDING SYRINGE TO HIS G TUBE. THIS ALLOWS THE GAS AND SOMETIMES EXCESS STOMACH FLUID TO BE RELEASED INTO THE SYRINGE. IF THE SYRINGE SHOULD BECOME FILLED, JUST CLAMP OFF THE TUBING, EMPTY THE SYRINGE APPROPRIATELY AND REPEAT THE PROCEDURE.

DREW'S EYES AND BEHAVIOR ARE MONITORED BECAUSE THEY ARE THE FIRST INDICATORS OF A SHUNT FAILURE.

AFTER RINSING THE FEEDING BAG IN THE MORNING, REMOVE THE MICKEY EXTENSION TUBE AND THROW OUT THE EMPTY USED BAG. DO NOT THROW OUT THE MICKEY EXTENSION TUBE!!

ALWAYS LEAVE THE EXTENSION TUBE'S SIDE PORT CLOSED (EXCEPT WHEN CLEANING IT). IF YOU DON'T, YOU'LL KNOW WHY WHEN YOU GIVE HIM HIS NEXT FEEDING THROUGH IT.

IN THE MORNING JUST RING THE DOOR BELL AND WALK ON IN. MUFFY HAS PROBABLY ANNOUNCED YOUR ARRIVAL ANYWAY.

THE FEEDING BAG IS ALWAYS EMPTIED BY GRAVITY NOT BY FORCE.

SINCE DREW IS A "RESTAURANT CRITIC" - HE REALLY ENJOYED HIS RECENT VISIT TO THE MACHINE SHED AT I94 AND ROUTE 164. IT WAS FUN, THE FOOD'S GREAT!

THE FAMILY POLICY OF NO SHOES IN THE HOUSE WAS ESTABLISHED DUE TO DREW'S CRAWLING. BY REMOVING SHOES THE AMOUNT OF DIRT ON THE FLOORS IS REDUCED. DREW'S HANDS, FEET AND CLOTHING STAY CLEANER AND HE STAYS HEALTHIER.

TRY TO PARK IN THE TURN AROUND AREA BY THE SHED AND BASKETBALL GOAL. THIS WILL REDUCE THE LIKELIHOOD OF YOUR VEHICLE BEING CUSTOMIZED BY CRUNCH!

WHEN DREW'S BRACES ARE REMOVED IN THE MORNING, PLEASE "CLOSE" THE VELCRO FASTENERS BUT DO NOT RUN THE FASTENER STRIPS THROUGH THE BUCKLES. CLOSING THEM KEEPS THEM FROM STICKING TO EVERYTHING WHEN THEY'RE STORED AND NOT RUNNING THEM THROUGH THE BUCKLES SAVES TIME WHEN THEY'RE PUT ON THE NEXT TIME.

ANYONE NEEDING AN INTRODUCTION TO DREW'S COMPUTER AND HIS SOFTWARE SHOULD SEE CHAD OR DAD. IT'S PRETTY EASY. REALLY!

LATER THIS MONTH DREW WILL BE GOING TO THE SPINA BIFIDA CENTER AT ST. MICHAEL HOSPITAL. THE CENTER'S PRIMARY FOCUS IN THE BLADDER STIMULATION PROGRAM. BY USING THE TES UNIT AT NIGHT, THE NERVES IN THE BLADDER AREA ARE STIMULATED. AS THE NERVES AWAKEN HE IS MORE LIKELY TO REALIZE THAT HIS BLADDER IS FULL AND THIS WILL ALLOW HIM TO DEVELOP BLADDER CONTROL.

DREW WEARS A NECK BRACE TO REDUCE TRAUMA TO HIS SPINAL CORD. THIS IS IMPORTANT BECAUSE THE ARACHNOIDITIS COULD IMPAIR GROWTH IN THIS AREA AS HE BECOMES A TEENAGER. FOR NOW THE SYMPTOMS ARE HEADACHES.

WHENEVER DREW IS TRANSPORTED IN A VEHICLE HE MUST HAVE HIS SEAT BELT ON. HE SHOULD BE SECURED IN A REGULAR SEAT, NOT IN HIS SCOOTER DURING TRANSPORTATION.

THE TWISTERS DREW WEARS WHILE WALKING, PULL ^{UP} ~~THE~~ FEET INWARD SO HE CAN WALK STRAIGHT.

DREW'S NEWS

BY DRAINING THE WATER TRAP IN THE A.M. RATHER THAN THE P.M. IT REDUCES THE CHANCE OF BACTERIA CONTAMINATION. THE EXTENSION TUBE IS LEFT ON THE FEEDING WHILE THE BAG IS FLUSHED WITH TAP WATER IN THE MORNING. TO REDUCE BACTERIAL CONTAMINATION DO NOT LET IT LAY IN THE SINK. REMOVE IT BEFORE DISPOSING OF THE FEEDING BAG.

SINCE WE LIVE IN A RURAL AREA, ALL WASTE WATER GOES TO A SEPTIC FIELD RATHER THAN TO A WATER TREATMENT PLANT. THE LIFE OF A SEPTIC FIELD IS LIMITED. OURS IS NOW MORE THAN 20 YEARS OLD AND HAS TECHNICALLY "FAILED". THIS MEANS THAT IT IS STILL USABLE BUT IT IS GOING TO HAVE TO BE REPLACED AT A COST OF BETWEEN \$3000 AND \$10,000. TO DELAY THIS EXPENSE WE SIMPLY REDUCE THE AMOUNT OF WATER CONSUMED - LESS BATH WATER, LESS LAUNDRY ETC. THIS IS NOT CRITICAL BUT WE SHOULD TALK ABOUT IT.

DID YOU KNOW THAT DREW HAS BEEN A POSTER CHILD FOR THE WAUKESHA COUNTY UNITED WAY CAMPAIGN?

DID YOU KNOW THAT THE SKELETON OF A TEENAGE BOY WITH SPINA BIFIDA WAS FOUND IN FLORIDA? CARBON DATING DETERMINED THAT IT'S 8000 YEARS OLD. THIS IS THE OLDEST KNOWN EVIDENCE OF SPINA BIFIDA. IT'S ALSO SIGNIFICANT BECAUSE IT INDICATED A SIGNIFICANT AMOUNT OF CARE HAD BEEN PROVIDED SO THE BOY COULD LIVE THAT LONG.

ARE YOU FAMILIAR WITH ENGAGING, DISENGAGING AND CHARGING DREW'S SCOOTER?

THE PHONES CAN LOOK INTIMIDATING BUT ASK FOR A DEMONSTRATION. THEY'RE EASIER TO USE THAN YOU THINK. THE SPEAKER PHONE CAN BE QUITE HELPFUL, THE HOLD BUTTON HELPS TOO AND AUTO DIAL SAVES LOOKING UP NUMBERS.

WE NOW HAVE A FAX MACHINE - SHOULD YOU NEED TO SEND A FAX. IF THE PHONE RINGS FOUR TIMES THE CALL IS AUTOMATICALLY PICKED UP BY THE FAX MACHINE, YOU'LL KNOW BY THE TONE. IF THE INCOMING CALL IS A FAX (YOU'LL KNOW BY THE SOUND) JUST HOLD ONTO THE RECEIVER UNTIL THE FAX MACHINE TAKES OVER, THEN HANG UP.

DOES ANYONE KNOW SOMEONE WHO IS INTO HOT AIR BALLOONING?

DREW'S RESTAURANT RECOMMENDATIONS INCLUDE CHING HWA, AN ORIENTAL RESTAURANT IN WAUKESHA LOCATED ACROSS FROM THE KOHL'S DEPARTMENT STORE, NEAR JACK GRIFFIN FORD. DREW LIKES THE SOUP BROTH BUT THE CASHEW CHICKEN IS FANTASTIC.

IF A HOME NON-MEDICAL EMERGENCY SHOULD ARISE AND DREW'S PARENTS AREN'T HOME, CONTACT KATHY ANZIVINO (ANN-ZA-VEEN-O). KATHY LIVES NEXT DOOR AT 621 MT. SNOWDON AND CAN BE REACHED AT 968-9666. KATHY DOES NOT WORK A FULL TIME JOB AND SHE IS WILLING TO STEP FORWARD AND TAKE ON ADULT RESPONSIBILITY. SHE IS NOT SKILLED IN ANY OF DREW'S MEDICAL NEEDS.

THE CONCHA SYSTEM MAKES AN UNUSUAL SOUND IF THE AIR LINE COMES OFF OF THE TOWER ON TOP OF THE CONCHA. WHEN YOU HEAR THIS IT MEANS THE AIR IS NOT FORCING THE HUMIDITY THROUGH THE TUBING TO DREW. IT ALSO MEANS THE CONCHA COLUMN WILL OVERHEAT AND BURN OUT.

DREW'S NEWS

CHECK IT OUT:

TRAINFEST IS BEING HELD AT STATE FAIR PARK ON NOV. 9 and 10 - EVERYTHING YOU WANTED TO SEE AND LEARN ABOUT MODEL RAILROADING.

ON 11/29 THE WORLD'S GREATEST COOKIE SALE IS BEING HELD AT THE WAUKESHA COUNTRY INN AT I 94 AND ROUTE T. THIS IS A HUGH CHRISTMAS BAKE SALE FOR ABOUT 40 CHARITIES. IT WILL BE PACKED AND SELLS OUT RAPIDLY.

ON 11/30, 12/1,7,8,14 & 15 OLD WORLD WISC. CHRISTMAS THROUGHOUT THE YEARS IN BEING HELD IN EAGLE.

ON 11/30-12/1 THE MID-CONTINENT RAILWAY MUSEUM HOSTS THE SANTA EXPRESS IN NORTH FREEDOM.

IS EVERYONE'S CPR CERTIFICATION CURRENT? I KNOW DREW'S PARENTS AREN'T.

DREW WILL BE VISITING HIS DENTIST SOON. WE USUALLY TRY FOR VISITS EVERY FOUR TO SIX MONTHS FOR CHECKUPS AND CLEANING DUE TO THE RAPID PLAQUE BUILDUP ON HIS TEETH. SINCE THE LIKELIHOOD OF HIS GUMS BLEEDING AT THESE VISITS IS HIGH, HE MUST BE GIVEN AN ANTIBIOTIC BEFORE HE GOES TO THE DENTIST.

TRASH ITEMS PLACED IN THE PAPER KITCHEN TRASH BAGS AND WASTE BASKETS ARE USUALLY BURNED. THIS IS DONE BECAUSE BURNING IS PERMITTED AND IT ALSO REDUCES THE VOLUME OF TRASH THAT MUST BE HAULED AWAY EACH WEEK. SIX CONTAINERS A WEEK IS NOT UNUSUAL IF BURNING IS NOT DONE. SINCE METAL, GLASS AND DIAPERS DON'T BURN AND CAN BE SMELLY THEY ARE KEPT OUT OF THESE CONTAINERS.

IF YOU HAVEN'T TRIED RAIN-X FOR YOUR CAR'S WINDSHIELD YOU REALLY SHOULD. THE HARDER IT RAINS THE BETTER IT WORKS. YOU'LL REALLY APPRECIATE IT WHEN YOU HAVE TO PASS A TRUCK IN A HEAVY DOWNPOUR. IT WORKS SO WELL IN A HEAVY RAIN THAT YOU MAY NOT EVEN NEED TO TURN ON YOUR WINDSHIELD WIPERS. AFTER THIRTY DAYS IT WEARS OFF AND IT MUST BE APPLIED AGAIN AND IN A LIGHT RAIN IT'S NOTHING SPECIAL BUT IN A HEAVY RAIN IT CAN'T BE BEAT.

DREW THE RESTAURANT CRITIC RECOMMENDS THE SIZZLER IN WAUKESHA. THIS SIZZLER IS LOCALLY OWNED AND THEIR FOOD IS DEFINITELY ABOVE AVERAGE. IF TONI IS WAITING ON YOUR TABLE THE SERVICE IS EXCEPTIONAL.

DREW'S DIAGNOSIS

1. SPINA BIFIDA (L 4-5)
2. ARNOLD CHIARI
3. ALLERGIES: LATEX, AUGMENTEN, PEDIZOLE, AMOXICILLIN
4. VP SHUNT
5. GASTROSTOMY TUBE (2.0 18 FR. MICKEY)
6. TRACH (5.5 BIVONA)
7. NYSTAGMUS
8. BOWEL AND BLADDER INCONTINENT
9. VISUAL AND HEARING IMPAIRED (GLASSES AND HEARING AIDS)
10. SEIZURES
11. CHRONIC ASTHMA
12. ARACHNOIDITIS
13. NON AMBULATORY
14. HAND TREMORS
15. ATTENTION DEFICIT DISORDER

	NAME	ROLE	PHONE	FAX #
HOSPITAL	MHO	HOSPITAL	800-347-9922	
HOSPITAL	WAUKESHA MEMORIAL	HOSPITAL	544-2201	
HOSPITAL	WISC. CHILDREN'S	HOSPITAL	266-2000	
DOCTOR	KOVNAR	NEUROLOGY		
DOCTOR	BALCOLM, ANTHONY	UROLOGY	527-8556	527-8620
DOCTOR	BESTE, DAVID	EAR, NOSE & THROAT	266-4660	
DOCTOR	BROWN, CHRIS	GASTRO INTESTINE	266-2000	
DOCTOR	GOSAIN, ARUN	PLASTIC SURGEON	266-2821	
DOCTOR	JONA, JUDA	SURGEON	271-6303	
DOCTOR	KELLY, KEVIN	ALLERGIST	257-6095	
DOCTOR	LEACH, CRAIG	PEDIATRICIAN	258-0606	258-1953
DOCTOR	RENNER, WILLIAM	DENTIST	549-3640	549-3511
DOCTOR	RICE, TOM	PULMONARY	266-3360	
DOCTOR	RICKERT, KEN	NEUROSURGEON	266-6440	
DOCTOR	RUTTHAM, MARK	EYE INSTITUTE	257-5821	
DOCTOR	ROLLEFSON, JAMES	DENTIST	786-1270	
DOCTOR	SCHWAB, JEFF	ORTHOPAEDIC	257-5434	454-4151
DOCTOR	SEFERT, TIM	OPTOMETRIST	367-6610	367-8120
DOCTOR	SPLAINGARD, MARK	REHABILITATION	266-2902	
DOCTOR	STEINHAUS, RANDALL	PSYCHIATRIST	355-2273	
	BECHER, BOB	SPEECH PATHOLOGIST	266-2900	
	BECKER, TIM	AUDIOLOGY	266-2934	
	BURKE, MARY	ORTHOPAEDIC	257-6016	
	FREIDHOFF, MARGE	BOWEL MANAGEMENT	456-4965	
	GUTHRICK, MARGE	STATE - KATIE BECKETT	800-362-3002	
	RAUEN, KAREN	SPINA BIFIDA CENTER	527-8556	527-8620
	STEVENS, LINDA	DIETARY	266-2000	
HARTLAND PT	SMITH, SUE	PHYSICAL THERAPY	367-6682	367-5960
KM TRANSPORT	BRUCE	MEDICAL TRANSPORTATION	521-2273	
REHAB DESIGNS	KACZMAROWSKI, KACZ	LEG BRACES	266-6990	266-6999
VCM	VCM	HOME EQUIPMENT SUPPLIER	774-7575	774-9339
WILKE'S PHARMACY	WILKE, TOM	PHARMACY	442-4400	442-1385
WALMART PHARMACY	SCHWARTZ, BOB	PHARMACY	646-3535	646-3575

REASONS FOR DREW'S MEDICATIONS

Aminophyllin - Respiratory (bronchial asthma)

Bactrim - Antibiotic (prevent bladder infections)

Bisacodyl suppository - Bowel stimulant (bowel management)

Depakene - For seizures

Folic Acid - Dietary supplement

Intal - Respiratory dilator, used with Ventolin

Nasal crom - Nasal & Bronchial dilator (bronchial asthma)

Pedameth - Buffer to balance pH of urine, reduces skin irritation & breakdown

Propulsid - For stomach irritation

Senokot - Bowel stimulant (bowel management), necessary due to lack of sensation

Sween Creams - Protect his skin from irritation & breakdown

Ventolin - Respiratory (bronchial asthma), used with Intal

Vitamins - Nutritional supplement with Fluoride

Zantac - For stomach irritation

DREW'S BASIC STUFF AND WHERE TO FIND IT

BY ITEM		BY STORAGE LOCATION	
ITEM	STORAGE LOCATION	STORAGE LOCATION	ITEM
CREAMS & OINTMENTS	BED END CABINET	FRONT CLOSET	"GO" BAG
DIAPERS	BED END CABINET	FRONT CLOSET	BAG FOR BRACES
DIAPER PAIL	BEDROOM CLOSET	LONG DRESSER	CLOTHING
HEARING AIDS	DRAWER UNDER BED	DRAWER UNDER BED	COLOGNE
CONCHA WATER	DRAWER UNDER BED	DRAWER UNDER BED	CONCHA WATER
NECK BRACE	DRAWER UNDER BED	BED END CABINET	CREAMS & OINTMENTS
COLOGNE	DRAWER UNDER BED	BEDROOM CLOSET	DIAPER PAIL
EYE GLASSES	DRAWER UNDER BED	BED END CABINET	DIAPERS
WRIST WEIGHTS	DRAWER UNDER BED	DRAWER UNDER BED	EYE GLASSES
"GO" BAG	FRONT CLOSET	DRAWER UNDER BED	HEARING AIDS
BAG FOR BRACES	FRONT CLOSET	KITCHEN CABINET	MEDICATIONS
MEDICATIONS	KITCHEN CABINET	DRAWER UNDER BED	NECK BRACE
CLOTHING	LONG DRESSER	TALL DRESSER	TOOTH BRUSH/PASTE
TRACH CARE SUPPLIES	TALL DRESSER	TALL DRESSER	TRACH CARE SUPPLIES
TOOTH BRUSH/PASTE	TALL DRESSER	DRAWER UNDER BED	WRIST WEIGHTS

DREW'S GO BAG CONTENTS

EQUIPMENT: AMBU BAG, STERILE TRACH, SUCTION CATHETERS, SMALL SPORT BOTTLE, TRASH BAG FOR DIAPER DISPOSAL, EMERGENCY SUCTION KIT

DIAPER NEEDS: DIAPERS (6), WIPES, PERI WASH, PERI BARRIER, SWEEN CREAM, PITTSBURGH PASTE

CLOTHING: PANTS, SHIRT, SOCKS

MEDICATIONS & FOOD: STERILE WATER, PEDIASURE WITH FIBER, FLUSH, LARGE SYRINGE, EXTENSION TUBE, 10cc SYRINGE, PLASTIC CYLINDER, AMINOPHYLN, DEPEKENE, PEDIAMETH, ZANTAC, FOLIC ACID, PROPULSID, BACTRIM

SNACKS: PRETZELS, PEANUT BUTTER, MISC. SEALED FOOD PACKETS

MORNING CARES

- 8:00 MEDICATIONS DELIVERED THROUGH FEEDING PUMP
- REMOVE LEG BRACES
- SHUT OFF TES IF IT WAS USED, REMOVE PATCHES & RECORD HOURS
- OXYGEN TURNED OFF
- CONCHA TURNED OFF & MASK REMOVED
- COMPRESSOR TURNED OFF
- SHUT OFF APNEA MONITOR
- DISCONNECT APNEA LEADS FROM PATCHES
- SHUT DOWN AND CLEAR FEEDING PUMP
- REMOVE & RINSE FEEDING BAG
- DIAPER CHANGED & CARES DONE
- DO G TUBE CARE & REPLACE PAD
- DO TRACH CARE & REPLACE PAD
- GET DREW DRESSED
- HEARING AIDS IN EARS & TURNED ON
- CLEAN EYE GLASSES AND PUT THEM ON DREW
- PUT ON HIS NECK BRACE
- PUT ON HIS WRIST WEIGHTS
- BRUSH HIS TEETH
- COLOGNE
- FILL PORTABLE OXYGEN TANK FOR SCHOOL
- EMPTY WATER TRAP
- EMPTY DIAPER PAIL AS NEEDED
- PUT SCHOOL SHOES ON

REQUIRED FOR SCHOOL

- SCOOTER *OR WHEELCHAIR*
- SUCTION PUMP
- GO BAG
- BRACES, TWISTERS & SHOES
- FILLED PORTABLE OXYGEN TANK
- SCHOOL BOOK BAG
- JACKET
- LONG PANTS

DREW'S TASTE TREAT LIST

DREW TASTES THE FOLLOWING ITEMS IN SMALL AMOUNTS – ONE TABLESPOON AT MOST. THEY ARE TREATS AND ARE NOT SUBSTITUTES FOR HIS REGULAR FEEDINGS. FOODS WITH ANY TEXTURE CANNOT BE EATEN BY DREW SINCE THEY WILL CAUSE CHOKING.

- 1. SMOOTH PEANUT BUTTER**
- 2. WHIPPED CREAM CHEESE**
- 3. PUDDING**
- 4. ICE CREAM**
- 5. CLEAR CHICKEN OR BEEF BROTH**
- 6. SMALL PIECES OF PLAIN CHOCOLATE (HERSHEY KISSES)**
- 7. MAYONNAISE**
- 8. CREAMY YOGURT**
- 9. PRETZELS (LICKS THE SALT OFF)**
- 10. TAPIOCA**
- 11. HONEY**

FLOW SHEETS
FOR A RECORD
OF DREW'S CARES
AND CONDITION

DREW'S MEDICATION LIST

Aminophylline (5 ml = 90 mg Anhydrous Theophylline)
 Bactrim, Pediatric Suspension (5 ml = 40 mg Trimethoprim & 200 mg Sulfamethoxazole with .3% Alcohol)
 Bisacodyl suppository (10 mg in Hydrogenated vegetable oil base)
 Depakene (5 ml = 250 mg)
 Folic Acid (1 mg per tab)
 Intal (2 ml = 20 mg cromolyn sodium)
 Nasalcrom (1 ml = 40 mg cromolyn sodium in purified water)
 Pedameth (5 ml = 75 mg Racemethionine)
 Propulsid (10 mg per tab)
 Senokot (5 ml = 8.8 mg sennosides)
 Ventolin (1 ml = 5 mg albuterol sulfate, inhalation Solution)
 Vitamins (.5 mg Poly.Vi.Flor)
 Zantac (1 ml = 15 mg Ranitidine Hydrochloride)

DREW'S MEDICATION SCHEDULE

5:30 AM	one puff ea.	Nasalacrom per nostril Ventolin Treatment (.5 Ventolin + 1 Vile Intal), clapping & suction after treatment
8:00 AM	7.5 cc 13.3 cc 4.0 cc 4.5 cc 10.0 cc one tab	Bactrim, Pediatric Suspension Pedameth Aminophylline Depakene Zantac Propulsid (crush and mix with sterile water) Tavist - PRN
10:00 AM	100 cc 1.0 ml one tab 30.0 cc	Pediasure (with fiber) feeding with 60 cc flush Vitamins Folic Acid (crush and mix with sterile water) Senokot (Sun., Tue., & Thu. only - CHECK WITH PARENTS FIRST)
Noon	100 cc one tab	Pediasure (with fiber) feeding with 60 cc flush Propulsid (crush and mix with sterile water)
1:30 PM	one each one puff ea.	Bisacodyl suppository (Sun., Tue., & Thu. only - after Senokot, CHECK WITH PARENTS FIRST) Nasalacrom per nostril <u>or</u> Ventolin Inhaler (3 puffs total at 2 minute intervals) then Intal Inhaler (3 puffs total at 30 second intervals), clapping & suction after treatment
2:00 PM	100 cc	Pediasure (with fiber) feeding with 60 cc flush
4:00 PM	100 cc 4.0 cc 4.5 cc one tab	Pediasure (with fiber) feeding with 60 cc flush Aminophylline (do not mix with the Pediasure) Depakene (do not mix with the Pediasure) Propulsid (crush and mix with sterile water)
6:00 PM	100 cc	Pediasure (with fiber) feeding with 60 cc flush
7:30 PM	7.5 cc 10.0 cc 13.3 cc one tab	Bactrim, Pediatric Suspension Zantac Pedameth Propulsid (crush and mix with sterile water) Tavist - PRN
8:00 PM		Start continuous Pediasure (plain) feeding (45 cc/hr., 540 cc total)
1:30 PM	one puff ea.	Nasalacrom per nostril Ventolin Treatment (.5 Ventolin + 1 Vile Intal), clapping & suction after treatment
Midnight	4.0 cc 4.5 cc	Aminophylline Depakene

DREW'S DAILY NURSING ASSESSMENT FLOWSHEET

DATE
HOURS

VITAL SIGNS:
HEART RATE?
O2 SATURATION LEVEL?
TEMPERATURE?

MON	T-AM	T-PM	WED	THU	FRI	SAT	SUN

MON	T-AM	T-PM	WED	THU	FRI	SAT	SUN

RESPIRATORY:
SECRETIONS?
SUCTIONING?
S.O.B.?
EXERTIONAL DYSPNEA?
WHEEZING?

PHYSICAL CONDITION:
NYSTAGMUS?
GASTROSTOMY SITE?
TRACH SITE?
HAND TREMORS?
HEADACHE?
LETHARGY?
FATIGUE?
PAIN?
IRRITABLE?
SEIZURES?

INTEGUMENT ASSESSMENT:
RASH?
PRESSURE SORES?
BRUISES?
REDNESS?
EDEMA?

GENTOURINARY:
DIAPERS, 3+?
URINE?
INCONTINENCE?
STOOL?

GASTROINTESTINAL:
CONSTIPATION?
GASTRIC PAIN?
INCONTINENCE?

GENERAL:
PRN MEDS USED?
L.O.C.?

INITIALS:

DREW WILLIAMS

VCM SUPPLY ORDER

NEED	UNITS	DESCRIPTION	PER MO.	LOCATED	RESERVE
	PAIR	APNEA MONITOR LEAD WIRES 40"	10 PAIR	MONITOR CABINET	
	EACH	TES STIMTEC LEAD WIRES, #78-7256	INC.	MONITOR CABINET	
	EACH	NEUROAID ELECT., 1x6 FOR TES, #56907794, 2/PKG	26 PKGS	MONITOR CABINET	
	EACH	NEURO ELECTRODES, #56903798, 2PR/PKG	18 PKGS	MONITOR CABINET	
	BOX	PORTEX TRACH THERMOVENTS, #570016, 50/BOX	1 BOX	MONITOR CABINET	
	BOX	DUODERM DRESSING, 4x4, #187610, 5 SHEETS/BOX	1 BOX	MONITOR CABINET	
	BOX	COTTON TIP STERILE APPLICRS, 6", MDS 20-2000	3 BOXES	MONITOR CABINET	
	BOX	DRAIN SPONGE 4x4 STERILE, #2391, 50/BOX	6 BOXES	MONITOR CABINET	CLOSET
	BOX	10 STERILE SPONGE 2x2, #2392, 70/BOX,	4 BOXES	MONITOR CABINET	CLOSET
	CASE	MEDLINE SUC CATH KIT, 8 FR, #DYND40958, 50/CASE	6 CASES	MONITOR CABINET	BASMT
	EACH	40% VENTURI (FROM VENTURI MASK), EACH	8 EACH	BED DRAWER	
	ROLL	TAPE 1 INCH 3M TRANSPORE, #1527-1, 12/BOX	7 ROLLS	BED DRAWER	
	EACH	MIC-KEY G. TUBE BUTTON, #0120-18-2.0, EACH	1 EACH	BED DRAWER	
	EACH	MIC-KEY EXTENSION SET, #0121-12, 5/BOX	4 EACH*	BED DRAWER	
	EACH	FOAM BELTING, EACH	INC.	BED DRAWER	
	EACH	TRACH TUBE TIES, DALE #240, EACH	15 EACH	BED DRAWER	
	PKG	PASSEY-MIUR SPEAKING VALVE, #005, 2/PKG	4/YR	BED DRAWER	
	EACH	BIVONA TRACH TUBE, #60P055, CUFFLESS	1 EACH	BED DRAWER	
	EACH	U/ADAPT STRAIGHT FOR CONCHA - BLUE	8 EACH	BED DRAWER	
	EACH	AIR LIFE CONCHA OXYGEN STEM WITH PLUG	8 EACH	BED DRAWER	
	EACH	ADAPTER MULTI ACCESS CAP FOR CONCHA OXYGEN	INC.	BED DRAWER	
	EACH	TEMPERATURE PROBES HUDSON CONCHA, #1635	10 EACH	BED DRAWER	
	EACH	CONCHA STERILE WATER, #381-50, 6/CASE	5 CASES	BED DRAWER	BASMT
	EACH	T - PIECE FOR CONCHA TUBING, #1077, EACH	10 EACH	BED DRAWER	BASMT
	SLEEVE	MED CUPS, 100 SLEEVE	BILLED	BED DRAWER	BASMT
	EACH	STERILE WATER 1000 ML, EACH 16/CS	1 CASE	BED DRAWER	BASMT
	CASE	CHUX UNDERPADS, 23X36, MSC 28-1248, 120/CASE.	1 CASE	BED DRAWER	BASMT
	BOX	GLOVES LARGE NON-STERILE VINYL, 100/BOX	3 BOXES*	DIAPER DRAWER	CLOSET
	BOX	GLOVES LARGE STERILE VINYL, 100/BOX	3 BOXES*	DIAPER DRAWER	CLOSET
	GALLON	CONTROL 3 GERMICIDE, PREMIXED, GALLON	1 GAL	CLOSET	BASMT
	CASE	PEDIASURE, WITH FIBER, #51806, 24/CASE	3.5 CASES	KITCHEN	BASMT
	CASE	PEDIASURE, PLAIN, # 51804, 24/CASE	4 CASES	KITCHEN	BASMT
	EACH	FEED SETS PUMP, ENTRACARE UK1000, 30/BOX	1 BOX	TOP REFRIG	BASMT
	EACH	MIC-KEY BOLUS FEEDING SET, 0123-12, EACH	4 EACH*	TOP REFRIG	
	EACH	SYRINGE 60cc, CATH TIP, #348682, EACH	8 EACH	TOP REFRIG	
	EACH	SYRINGE 20cc, LUER LOK, #9661, EACH	5 EACH	TOP REFRIG	
	EACH	SYRINGE 10cc, CATH TIP, #301604, EACH	5 EACH	TOP REFRIG	
	EACH	WATER TRAPS, HUDSON #1742, EACH	10 EACH	BASMT	BASMT
	EACH	CONCHA COLUMNS, #382-70, EACH	5 EACH	BASMT	BASMT
	EACH	OXYGEN EXTENSION TUBING 7 FEET LONG, #1112, EACH	16 EACH	BASMT	BASMT
	EACH	OXYGEN TUBING 25 FEET LONG, #1119, EACH	6 EACH	BASMT	BASMT
	BOX	SUCTION TUBING, MEDI-VAC, N6100, 100 FEET/BOX	1 BOX	BASMT	BASMT
	EACH	TRACH MASK ADULT, HUDSON #1075, EACH	12 EACH	BASMT	BASMT
	EACH	MICRO MIST NEBULIZER, HUDSON, EACH	12 EACH	BASMT	BASMT
	CASE	CORRUGATED TUBING, #001849, 100 FEET/CASE	1 BOX	BASMT	BASMT
	EACH	EGG CRATE FOAM BED PAD, EACH	1/YR		

INSTRUCTIONS: ORDER NO MORE THAN THE "PER MONTH" LIMIT

INSTRUCTIONS: MONTH LIMITS WITH "*" ARE LIMITED TO THAT TOTAL AMOUNT FOR ALL "SIMILAR" ITEMS WITH "**"

DREW WILLIAMS

ORDER FOR WILKE PHARMACY

<u>NEED</u>	<u>UNITS</u>	<u>ITEM</u>	<u>PER MO.</u>	<u>LOCATED</u>
	BAG	DIAPERS, CASE	15 BAGS	BED DRAWER
	TUBE	BACTROBAN		BED DRAWER
	PKG	HEARING AID BATTERIES, 4/PKG		BED DRAWER
	TUBE	NEOSPORIN		BED DRAWER
	EACH	PERI-CARE BARRIER CREAM		BED DRAWER
	EACH	PERI-WASH, PINT BOTTLE		BED DRAWER
	EACH	PITTSBURG PASTE		BED DRAWER
	EACH	SWEEN CREAM		BED DRAWER
	TUBE	TRIPLE ANTIBIOTIC OINTMENT		BED DRAWER
	BOX	UNISOLVE WIPES, BOX		BED DRAWER
		EMLA CREAM		MONITOR CABINET
	EACH	HYDROGEN PEROXIDE		MONITOR CABINET
	BOX	INTAL	1 BOX	MONITOR CABINET
	BOTTLE	NASELCROM	2 BTLS	MONITOR CABINET
	BOX	SALINE SOLUTION AMPULES, 100/BOX		MONITOR CABINET
	PKGS	VENTOLIN	3 PKGS	MONITOR CABINET
	BOTTLE	AMINOPHYLLINE	2 PINTS	KITCHEN
	BOTTLE	BACTRIM	2 PINTS	KITCHEN
	BOTTLE	DEPAKENE	1 PINT	KITCHEN
	BOTTLE	PEDAMETH	2 PINTS	KITCHEN
	BOTTLE	POLY.VI.FLOR VITAMINS	2 BTLS	KITCHEN
	BOTTLE	SENOKOT	2 PINTS	KITCHEN
	BOTTLE	TAVIST	.5 PINT	KITCHEN
	BOTTLE	ZANTAC SYRUP	2 PINTS	KITCHEN
	BTL	FOLIC ACID TABLETS, 30/ BOTTLE	1 BTL	KITCHEN
	BTL	PROPULSID TABLETS, 120/BOTTLE	1 BTL	KITCHEN
		BISACODYL SUPPOSITORY		REFRIG

LETTERS TO
AGENCY CONCERNING
NURSING COVERAGE

OLD HISTORY
AGENCY WAS FIRED
& REPLACED BY
INDEPENDENT
NURSING

Drew Williams' Family Nursing Coverage Concerns

The available nurses are not used (scheduled) effectively and consistently.

Nursing schedules are not consistent - Both the client and the nurses want consistent scheduling. See the table # 1 covering the "10 week measure of nursing schedule consistency ..." for the actual result.

"Policy" requires that full time nurses cover holidays and weekends too.

Between 6/1/94 and 8/31/94 there are 26 Saturdays and Sundays, nine of these days have been staffed by full time nurses. Marilyn Sherman has been the scheduled nurse 7 of these 9. Three times part time nurses were scheduled and 14 days were left without nursing coverage. The 4th of July Holiday shift was covered by a part time nurse.

Qualified nurses are not scheduled even though they are "available". Only 8 of the 10 qualified nurses were scheduled in July & August.

In August five "part time" nurses were available. Four shifts were scheduled for three of these nurses, no shifts were scheduled for the other two.

"Back up" exists only on paper - rarely if ever have missed shifts been filled.

Examples include: Aug. 5 day shift, June 22 day shift, June 20 day shift, May 10 day shift, March 24 day shift, March 22 night shift, March 1 day shift

"Critical shifts" (when both parents work or no parents are available) are scheduled with quality nurses that have attendance problems.

Example Friday August 5, 1994.

"On call" nurses are not familiar with the case - an answering machine or answering service could provide the same quality result.

Special situation requests have been resolved by the client and nurses working together to address the problem - not the agency. Examples include my Mother's funeral, two Milwaukee Brewer baseball games, family trip to Great America and a wedding.

Problems with nurses are only resolved by the client asking that the nurse not return to the case. Shouldn't the agency take corrective action?

Case management should be more than case maintenance.

The case manager should be a communications artery. This person should monitor the client's overall medical needs and facilitate an understanding of the effects of medication and the effectiveness of the care plan. This person should be able to communicate the patient and family needs to medical professionals as needed.

The case manager should have hands on experience with the patient's cares.

The case manager should be an advocate for the patient so that new opportunities and treatment are made available to meet the patient's needs. The patient's unique needs in areas such as continence, therapy, mobility, education, diet, behavior, transportation etc. must be addressed regularly.

Pressures and stresses within the family must be recognized and addressed. This should be done in the collective interest of the patient, the family, the nurses and the Agency.

The case manager should monitor the training of nurses and observe the nurses proficiency first hand.

10 WEEK MEASURE OF NURSING SCHEDULE CONSISTENCY FROM 6/19 TO 8/27/94

SHIFT	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
DAY	2/3/7	3/10/0	2/10/0	3/9/1	3/5/5	2/10/0	3/4/6
EVENING	-	3/5/5	1/10/0	4/8/2	2/9/1	2/2/8	-
NIGHT	-	0/0/10	1/9/1	0/0/10	1/9/1	0/0/10	-

EXPLANATION

THE FIRST NUMBER INDICATES HOW MANY DIFFERENT NURSES HAVE BEEN

SCHEDULED TO WORK THIS SHIFT IN THE 10 WEEK PERIOD

THE SECOND NUMBER INDICATES HOW MANY SHIFTS WERE SCHEDULED

THE THIRD NUMBER INDICATES HOW MANY SHIFTS WERE NOT SCHEDULED

	MARCH, 1994	MAY, 1994	JUNE, 1994	JULY, 1994	AUGUST, 1994
QUALIFIED NURSES AVAILABLE	8	8	10	10	10
QUALIFIED NURSES SCHEDULED	8	8	9	8	8
PERCENTAGE OF NURSES SCHEDULED	100.00%	100.00%	90.00%	80.00%	80.00%
SHIFTS SCHEDULED IN MONTH	60	58	54	41	48
DAYS IN THE MONTH	31	31	30	31	31
HOURS SCHEDULED IN MONTH	463.5	468	403.5	312.5	376.5
HOURS SCHEDULED PER WEEK	105	106	94	71	85
HOURS OF ELIGIBILITY PER WEEK	133	133	133	133	133
PERCENTAGE OF ELIG. SCHEDULED	79.00%	80.00%	71.00%	53.00%	64.00%
HOURS SCHEDULED PER DAY	14.95	15.1	13.45	10.08	12.15

COMMENTS: FROM MARCH THROUGH JULY MORE QUALIFIED NURSES WERE AVAILABLE
 FROM MARCH THROUGH JULY THE NUMBER OF SCHEDULED NURSES DECLINED
 FROM MARCH THROUGH JULY THE NUMBER OF NURSING SHIFTS DECLINED
 FROM MARCH THROUGH JULY THE NUMBER OF SCHEDULED NURSING HOURS DECLINED

Signatures Continued
For Chairmen Grobschmidt and Grothman and members of the Joint
Committee for Review of Administrative Rules

- ⑦ Leonard Browne
645 E. Norwich St.
Milwaukee, WI 53207
- ⑧ Diane Lukas
1009 E. Ohio Ave.
Milwaukee, WI 53207
- ⑨ Nancy Alston
2816 N. 124th
Wauwatosa WI 53222
- ⑩ Myrna R. Hernandez
1142 E. Walworth Ave. #4
Milwaukee, WI 53212
- ⑪ Tony L. Podes
5659 N. Green River Pkwy.
Glendale, WI 53209
- ⑫ Linda C. Caumlael
8112 Forest Hill Ct
Greenfield WI 53250
- ⑬ Tom Jack
2020 E. Webster Pl.
Milwaukee, WI 53211
- ⑭ Dawn Richardson
1425 Underwood Ave #6
Wauwatosa, WI 53213

Dear Chairman Grobschmidt, Grothman and Members of the JCRAR:

I am very concerned about the treatment of medically fragile children and how life has become so much more difficult for them and the families caring for them. This has come about in the way they are being treated by the Bureau of Health Care Finances.

At present BHCF authorizes private duty nurses, (PDN), hours for the care of medically fragile dependent children. These children have recently become the focus of the BHCF cutbacks by taking away the nursing care orders by the child's physician. They have also created arbitrary guidelines for the distribution of authorized PDN care. This might meet the needs of the BHCF but it does not meet the needs of the medically fragile child being cared for at home.

It has become apparent that some very important items need to be addressed immediately. It is wrong that a program which is supposed to help children stay with their families, is treating the child and family in such a wrongful unjust manner.

- 1) Informal policy making by the BHCF must be STOPPED.
 - a) Informal policy changes occur to meet the department needs and do not reflect the needs of the child recipient.
 - b) It is subject to the bias of individual interpretation, which may change at any given moment and may not take into account the quality of life for the child.
 - c) The life of the child and family gets thrown into turmoil when the "rules" as they know them change.
- 2) BHCF should be required to establish policies for the department by formal administrative rules; starting immediately!
- 3) The desire of BHCF to control the exact hours per day does not treat the child fairly and respectfully.

The PDN hours that have been authorized by the BHCF should be distributed as deemed fit by the family of the recipient child. Twenty-four hour care in any day is acceptable for any reason providing it does not exceed the monthly allotment of hours. This supports the family in their ability to maintain the child's medical needs from day to day and the needs of the family which greatly vary one from another. This is how PDN hours were distributed in the past. It was more successful in meeting the needs of the medically fragile child being home with their family.

The children and their families are counting on this committee to immediately return to their former policy which allowed the medically fragile child to receive the best possible care.

Sincerely,

Phyllis Taparis

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Sincerely,

Michele Jones

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Sincerely,

Jane Wolf
Gerry Wolf

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A handwritten signature in cursive script, appearing to read "Grant Jones".

Sincerely,

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Sincerely,

Julian R. Plaster

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At present BHCF authorizes private duty nurses, (PDN), hours for the care of medically fragile dependent children. These children have recently become the focus of the BHCF cutbacks by taking away the nursing care orders by the child's physician. They have also created arbitrary guidelines for the distribution of authorized PDN care. This might meet the needs of the BHCF but it does not meet the needs of the medically fragile child being cared for at home.

It has become apparent that some very important items need to be addressed immediately. It is wrong that a program which is supposed to help children stay with their families, is treating the child and family in such a wrongful unjust manner.

- 1) Informal policy making by the BHCF must be STOPPED.
 - a) Informal policy changes occur to meet the department needs and do not reflect the needs of the child recipient.
 - b) It is subject to the bias of individual interpretation, which may change at any given moment and may not take into account the quality of life for the child.
 - c) The life of the child and family gets thrown into turmoil when the "rules" as they know them change.
- 2) BHCF should be required to establish policies for the department by formal administrative rules; starting immediately!
- 3) The desire of BHCF to control the exact hours per day does not treat the child fairly and respectfully.

The PDN hours that have been authorized by the BHCF should be distributed as deemed fit by the family of the recipient child. Twenty-four hour care in any day is acceptable for any reason providing it does not exceed the monthly allotment of hours. This supports the family in their ability to maintain the child's medical needs from day to day and the needs of the family which greatly vary one from another. This is how PDN hours were distributed in the past. It was more successful in meeting the needs of the medically fragile child being home with their family.

The children and their families are counting on this committee to immediately return to their former policy which allowed the medically fragile child to receive the best possible care.

Sincerely,

Daphne Merty Allen

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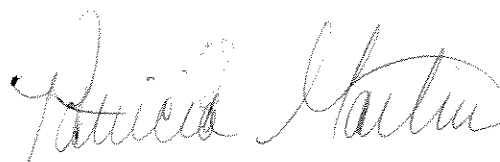
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A handwritten signature in cursive script, appearing to read "Patricia Martin". The signature is written in dark ink and is positioned to the right of the word "Sincerely,".

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John L. O. Jones

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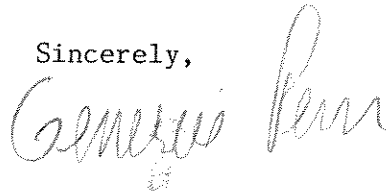
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