

JOHN HUDSON UPDATE

1.

SO WHAT DOES A TYPICAL 4 YEAR OLD WITH EPIDERMOLYSIS BULLOSA (EB) DEAL WITH ON A DAILY BASIS? SOME THINGS ARE BETTER THIS YEAR, SOME THINGS ARE WORSE. SO HERE GOES.....

WHAT'S NOT SO GOOD?

- JOHN HUDSON'S **WEIGHT** IS NOT KEEPING UP AS IT SHOULD. THIS IS A RESULT OF THE INTERNAL BLISTERS WHICH AFFECT HIS ESOPHAGUS, STOMACH AND INTESTINE. HE IS ON HIGH CALORIE DRINKS TO FORCE MORE CALORIES AND PROTEIN IN, BUT WITH LITTLE SUCCESS.
- **THROAT PROBLEMS** PERSIST. ROUGH AND SHARP FOODS CAN DAMAGE THE ESOPHAGUS LEADING TO BLISTERS, OCCLUSION, CHOKING AND VOMITING. JOHN HUDSON LOVES POTATO CHIPS — BUT THEY CAN BE DEADLY FOR A KID WITH EB.
- JOHN HUDSON HAS TWO **DYSPLASTIC NEVI** ON HIS FACE, WHICH ARE CONSIDERED RISKY AND ? PRE-CANCEROUS. IN ANYONE ELSE, THEY WOULD BE REMOVED, BUT WITH EB, THEY ARE MONITORED AND PHOTOGRAPHED TO MONITOR CHANGES. UUGGHHH.
- JOHN HUDSON HAD HIS FIRST BOUGHT OF **DENTAL WORK** DUE TO CAVITIES AND GUM EROSION. THIS IS EXPECTED, AS THE TEETH ARE MADE OF THE SAME EPITHELIUM AS THE SKIN. WE ARE TRYING HARD TO MANAGE HIS TEETH SO THAT HE CAN EAT WELL TO GAIN WEIGHT — THIS IN SPITE OF THE CONSTANT BLISTERS IN HIS MOUTH AND TONGUE.
- JOHN HUDSON'S **FINGERS** ARE CONTINUING TO CURL AND LOOSE SHAPE. IN SPITE OF O.T. AND ATTEMPTS TO WEAR HAND SPLINTS, HIS WEB SPACES ARE CLOSING AND HE IS HAVING TROUBLE WITH FINE MOTOR SKILLS. WE ARE HOPING HAND SURGERY TO STRAIGHTEN THE FINGERS IS FAR OFF.
- JOHN HUDSON'S **ZINC LEVELS** REMAIN BELOW NORMAL IN SPITE OF DOUBLING HIS DAILY DOSE OF ZINC. THIS IS LIKELY INTERFERING WITH HIS WOUND HEALING AND SKIN INTEGRITY.
- **FEET AND SHOES** REMAIN ANOTHER PROBLEM. HE HAS BEEN WEARING THE SAME PAIR OF CUSTOM MADE SHOES FOR OVER A YEAR. MULTIPLE ATTEMPTS TO MAKE NEW SHOES, WHICH HE CAN TOLERATE AND WALK IN, HAVE NOT FARED WELL. THIS IS AN ONGOING PROBLEM.
- **DRESSING CHANGES AND BATHS** REMAIN A DAILY PAINFUL, AGONIZING ORDEAL WITH RELENTLESS AMOUNTS OF FEAR, SCREAMING, AND CRYING. PAIN MEDICATION DID NOT WORK, NOR DID ANTI-ANXIETY MEDS, SO THIS GOES ON IN A TERRIBLE, HEART-BREAKING FASHION.
- THE MOST DIFFICULT PROBLEM JOHN HUDSON IS HAVING OF LATE CONCERNS HIS EYES. THE **CORNEAL EROSIONS** ARE BECOMING MORE FREQUENT AND LASTING LONGER. THESE ARE VERY PAINFUL AND REQUIRE DAYS TO HEAL WHILE HE IS MEDICATED AND KEPT IN A DARK ROOM UNABLE TO SEE. THERE IS NO TREATMENT FOR THIS (AS WITH ALL THINGS MENTIONED ABOVE) OVER FOR THE **GOOD NEWS** →

THANK GOD WITH THE BAD, THERE IS ALWAYS SOMETHING GOOD AS WELL.

SO WHAT IS BETTER?.....

- JOHN HUDSON IS ATTENDING **PRE-SCHOOL** 3 DAYS A WEEK (WHEN HE IS WELL) AND HAVING A GREAT EXPERIENCE. HE HAS A FEW LITTLE GIRL FRIENDS WHO LOOK AFTER HIM AND HIS NURSE, DIANE, IS THERE WITH HIM TO GET HIM THROUGH THE DAY.
- THE MOST RECENT BLOOD WORK SHOWED JOHN HUDSON'S **IRON LEVELS** HAVE IMPROVED SLIGHTLY. GOOD NEWS FOR WOUND HEALING AND FOR BATTLING ANEMIA.
- WE ARE HAVING SOME LUCK TREATING HIS **WOUNDS** WITH MANUKA HONEY WHICH IS A MEDICAL GRADE HONEY FROM NEW ZEALAND. IT IS HARD TO ACQUIRE AND EXPENSIVE, BUT HAS WONDERFUL HEALING PROPERTIES.
- A TRIP TO THE **CARDIOLOGIST** FOR AN ECHOCARDIOGRAM SHOWED JOHN HUDSON'S HEART IS NOT ENLARGED, AS WAS SUSPECTED.
- **SKIN INFECTIONS** HAVE BEEN A BIT BETTER THIS YEAR, PERHAPS THANKS TO THE WONDERFUL JOB DONE BY HIS NURSES, HIS NEW BATHROOM AND THE HONEY. VERY GOOD NEWS.
- JOHN HUDSON FINALLY **TOILET TRAINED** A FEW MONTHS AGO AND IS DOING VERY WELL. AS A RESULT, HIS BUTT IS DOING WELL ALSO 😊
- JOHN HUDSON'S **BATHROOM DOWNSTAIRS** IS FINISHED AND FABULOUS. THERE IS ROOM FOR SUPPLIES, HE IS USING THE TUB AND WE ARE IN THE PROCESS OF INSTALLING A HUMIDEX TO REMOVE MILDEW FROM THE AIR. WHAT A RELIEF TO HAVE HIM OUT OF THE KITCHEN SINK!
- **HUDSON'S HOPE FOUNDATION, INC.**, NAMED AFTER JOHN HUDSON, IS STILL WAITING FOR IRS APPROVAL. IT COULD BE ANY DAY, WEEK OR MONTH. WE ARE WAITING FOR THIS TO BECOME A REALITY AS THERE ARE SO MANY KIDS AND PEOPLE WHO WILL BENEFIT FROM THE FOUNDATION, NOT TO MENTION THE AWARENESS AND RESEARCH FOR A CURE THAT THE FOUNDATION WILL SUPPORT.
- JOHN HUDSON RECEIVED A WONDERFUL WISH FROM THE MARTY LYONS FOUNDATION AND WILL BE GOING TO **DISNEY WORLD** – WITH THE WHOLE FAMILY IN FEBRUARY. HE SO DESERVES TO HAVE SOME FUN AND FORGET ABOUT THE PAIN AND DAILY SUFFERING. KALILLA AND TEAK AND EXCITED AND WE CANNOT WAIT TO GO!

THAT'S ALL THE NEWS FOR NOW. THANK YOU FOR REMEMBERING JOHN HUDSON AND PLEASE KEEP HIM, HIS NURSES, DOCTORS AND RESEARCHERS IN YOUR PRAYERS.

HUDSON'S HOPE FOUNDATION, INC.

“WHERE THERE IS DOUBT, LET ME SOW FAITH,
WHERE THERE IS DESPAIR.....HOPE.”

-ST FRANCIS

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