



October 15, 2011

Dear Friends,

Cub Pack 21 is planning two fundraising events for our friend and fellow Scout, John Hudson Dilgen. John Hudson is a Jr. Webelo Scout in Cub Pack 21. As his Scout Family, we are reaching out to you on his behalf.

**First, here is a brief portrayal about our friend, John Hudson Dilgen:**

John Hudson Dilgen suffers from a rare genetic skin disease called Recessive Dystrophic Epidermolysis Bullosa, or RDEB. It is one of the more severe forms of EB. EB is caused by a lack of anchoring fibrils, the velcro which holds the top layer of skin (epidermis) to the layer below (dermis). John Hudson's skin is fragile and has wounds similar to second and third degree burns over most of his body, both internally and externally. Blisters also affect the eyes, mouth, esophagus and even his internal organs and he has difficulty eating and swallowing. John Hudson is bandaged from head to toe daily, including soaking in either bleach or vinegar, followed by medications. He makes routine trips to Cincinnati Children's Hospital where his esophagus is often dilated due to closure from blisters and where his other medical care is coordinated.

EB is a chronic, terminal disease. Most children with John Hudson's severe form of EB eventually succumb to anemia, failure to thrive and infection. Children who live longer usually succumb to squamous cell carcinoma. EB is not contagious and there is currently no cure. Research in gene therapy and stem cells is proving to be promising, but is still dangerous and with uncertain outcomes.

John Hudson is now 9 years old. He has had a very bad year with his feet. The wounds have been so bad he has not been able to walk for days and weeks at a time. There has literally been no skin on his heels. He is being carried to bed, the bathroom, and to the car. The pain was unbearable for him and so sad to watch. He continues to have episodes of erosions in his corneas, which leave him unable to see and of course, in excruciating pain.

Luckily there is also some good news, a small silver lining. John Hudson is playing drums in his school band! He bi-skis with the Adaptive Program at Windham Mountain and this year won the Spirit Award which is awarded to that skier who not only demonstrates a love of skiing, but a love for life, overcoming obstacles to achieve. JH sang in his school talent show, spends time with his bestest friend, Victoria and learned to swim!

His family's goal for this year is to find a way to better adapt their yard and car for John Hudson. He has an electric wheelchair that he cannot use because their house, yard and car are not accessible. Considering how difficult it has become for him to walk, this is unfortunately, something that needs to be addressed as soon as possible.

**About our fundraising efforts:** Our first fundraiser is being held by the young men of Cub Pack 21 themselves. A walk-a-thon, which we are calling the “John Hudson Dilgen – Walk for Wheels”. Our first mission is to recruit fellow “Walkers” because the more walkers we have, the greater the gift to John Hudson and his family.

The “Walk for Wheels” will take place in Tottenville. The walkers will circle the blocks surrounding PS 1 and IS 34 for as many laps as they can (up to 5 laps around, or approx. 2 miles). They will collect a flat fee donation from as many sponsors as they can. It is our hope that each walker collect a minimum of \$5 per sponsor. It is our goal that through these donations our Scouts and fellow “Walkers” can raise enough money to help John Hudson’s family put together a down payment for a new, handicapped accessible vehicle.

Our second fundraiser is being held by the adult committee members of Cub Pack 21. We will be hosting a Double-Decker Night Out at the South Shore Swim Club. In one room, there will be a Texas Hold’em Tournament. In the second room, Bingo! A night out that is not to be missed. There will be food, raffles, prizes and a 50/50 drawing. We hope that you will spread the word and invite your friends to join us for this pre-holiday madness night out. Our goal is to raise additional funds towards the purchase of a handicapped accessible vehicle and/or to make necessary modifications to their property. With your help we can achieve our goal!!! What better way to celebrate the beginning of the holiday season, than to help a child and family who desperately need it.

**What we are asking of you:** There are several ways in which you can help us with our efforts to raise EB awareness and assist the Dilgen family with their needs. For our “Walk for Wheels”, you can encourage your children, students, or friend’s children to walk with us. Did I mention that the route passes right in front of John Hudson’s home? Wouldn’t it be great for him to witness such an outpouring of support from his friends and community as the walk-a-thon takes us right past his house? The date of our walk is Saturday, November 5<sup>th</sup>. Sign in at 10 a.m. and the walk is scheduled to begin at 11:00 a.m. A registration form is attached. There is no over-head associated with this event and every penny will go directly to John Hudson Dilgen.

For our Texas Hold’em / Bingo night, you can spread the word and invite as many people as you can to join us. The date for this event is Friday, November 18<sup>th</sup>. More details will follow soon, but in a nutshell we can tell you that the cost to buy in for the Texas Hold’em tournament will be \$125 of which you will receive \$100 in chips and the other \$25 will cover the cost of food, soda, water and beer. The theme for our Bingo is a BYOBingo. The cost for entry will be \$20 and we ask that you bring a small prize with a value of \$10. This can be anything from scratch-off tickets, to gift cards or a gift certificate for a manicure. The choice is yours. Your \$20 entry fee will secure your seat and include one 3-on Bingo sheet, 5 raffle tickets, & food. Feel free to BYOB for this event!! We will play until we run out of prizes and then the raffles will begin. A 50/50 drawing will be held at the end of the night and tickets will be sold simultaneously throughout both events.

If the dates don’t work for you, but you still want to help, you may do so by donating prizes, raffle baskets or gift certificates. You may even choose to make a directed donation to John Hudson himself. Those checks should be made payable to: John Hudson Dilgen. Anything you can give would be greatly appreciated and every dollar helps us to reach our goal.

For more information, or to arrange to make a donation, please contact Lucy Schwarz at 917-803-7382 (Lschwarz@si.rr.com) or Eric Knutsen at 347-400-1072 (Eric1075@aol.com). We thank you in advance for your kind consideration and generosity.