

## PLEASE HELP by Joining an E-Mail Campaign for Karl Lebensorger, St. Pat's Alumni



*Hi Everyone! We are asking if you could PLEASE pass this on to your friends and family. This tough 47-year-old pictured above is Karl Lebensorger. He is an alumni of St. Patricia. His girls (April and Rachel) attended CCD and participated in sports at St. Pat's and Karl was involved with assistant coaching at St. Pat's. Karl was an active dad here at St. Patricia. Karl and his family attend church regularly at St. Pats. The family is need of some help. They are requesting you drop them a note with your email address so they can put you on an email list. (See below for more info on what the family is doing). All they're asking is for an email address and everyone to send a letter. Could you please help. Thanks and please keep Karl in your prayers!  
PS. Please feel free to forward this write-up to everyone! Thank you!*

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(This is an email received from Karl's relative on October 29.)

I got this message from Nadine and thought I'd share. Karl was accepted into a treatment study in Indiana. When the hospital tried to get approval from BCBS, they were turned down. They had told him he had about a 70 percent chance to beat the cancer, the treatment involved implanting 3 "BB's" in the area, then, several weeks later, after a series of precise calculations, they would do the proton treatment. They have only one chance to get it right, they can't do it again. He was told he had about 6 weeks before the tumor reached the brain stem, after which it would be too late.

The first phase of the treatment will be well over \$200,000 (I believe). The hospital said they would start the treatment (implant the BB's) if they paid \$80,000 up front. Since he didn't have \$80,000, he didn't go. (Their out-of-pocket medical expenses, this year alone, have been over \$27,000.) Now the hospital is booked up til Dec., which will be too late. They are trying to get through to someone at the hospital who can get him in in time.

Lena is writing an article for the Tribune, and Lena and Nadine have Good Morning America (possibly) interested in the story. In the meantime, we're organizing an email campaign to encourage BCBS to cover the treatment. The information is in Nadine's email, below. We would be grateful if you would consider joining the email effort. **Please contact Nadine's sister at [fightersforkarl@yahoo.com](mailto:fightersforkarl@yahoo.com)** and ask her to add you to the list. Please forward this to anyone who might be interested. Thanks.

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(This is the email she received from Karl's wife, Nadine Lebensorger)

The reason I am sending you this email is to make you aware of the fact that Karl's insurance, Blue Cross Blue Shield of Illinois and my insurance, Blue Cross Blue Shield of Ohio, **WILL NOT PAY** for Karl's only treatment option left available to him to treat the tumor in his head. Karl is in need of proton treatment - his new cancer is located 2-cm's off the stem of his brain and it is too large to surgically remove and conventional radiation is no longer an option for him because of the amounts of radiation he already had. Chemotherapy alone will not work. Proton treatment, according to all of Karl's doctor's, is his only hope at survival!

Blue Cross Blue Shield (BC/BS) said that the treatment "is not medically necessary" and "experimental." This is not true. It is medically necessary because it is the only treatment Karl can now have. It is not experimental; it's approved by the FDA, Medicare covers it and most insurance companies cover it. Please go to [www.mpri.org](http://www.mpri.org) to get information on proton treatment.

My sister in law, Debbie Vitha-Nolan is planning a mass emailing to the CEO and VP of BC/BS - we need email addresses and as many people to send this email letter on Karl's behalf.

She will add your email to the list and as soon as the letter is complete and a date to send the letter has been set, she will email you what you need to send to BC/BS.

I will truly appreciate everyone's help and support in getting this news across the BC/BS. Please email Debbie and help us send a message to BC/BS that they cannot determine who lives and who dies. Thank you. Nadine Lebensorger

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#### KARL'S TIMELINE:

1st Cancer Diagnosed February 1981- very rare cancer, Rhabdomyosarcoma of the left maxillary sinus, Treatment consisted of radiation and chemotherapy. Karl and his mother would fly monthly to The National Institutes of Health (NIH) in Bethesda, MD for treatments.

2nd Cancer - Diagnosed March 1982 - return of the Rhabdomyosarcoma - in lymph node in left side of neck - just beyond the original field of radiation. Treatment consisted of freezing Karl's own bone marrow, additional radiation and intensive chemotherapy plan. The intense chemo of five treatments where each treatment became more intense. The last treatment landed him in a plastic bubble room for 36 days where he became so ill that he needed his own bone marrow to bring his white cell level up to a normal level. It took Karl a few months to recover and regain his strength - he went from 210 Lbs. to 109 when we came home from the 2 years of treatment.

We were then married on May 13, 1984. A couple weeks before the wedding the doctors thought that Karl may have relapsed, but it turned out to be an infection. We were told we most likely would never have children because the treatment he had made him sterile. After pursuing our adoption options, we found out his fertility returned and we were expecting our first baby - we found out in September of 1988.

April 12, 1989 we had our first daughter, April Elizabeth. On June 30, 1991 we had our second daughter, Rachel Marie. On July 20, 1991 Karl was rushed back to NIH as a CT scan showed another tumor. It was my birthday and I was nursing our daughter when he came into the room with his face all blown up - he immediately went to the ER where they ran a CT scan and said it looked like cancer. He flew out to NIH that afternoon. The next morning I received a call from the hospital that I needed to get there that the cancer was back. I had to farm out the girls - my family took April and Karl's mom took Rachel since she was only a month old. We were at NIH for 2 weeks and luckily it turned out to be an infection and not cancer. He was on IV antibiotics for 2 weeks because the infection was so bad.

Around 1999 Karl's teeth started to fall out on the left side where all the radiation was. His face was noticeably starting to "cave-in" and his eye began to look like it was sinking in his head. We tried to get NIH to take him back, but too many years had lapsed and they could not take him as a patient. They put us in touch with The University of Chicago Hospital where Karl met with Dr. Robert Walton, a plastic surgeon. Dr. Walton felt that Karl would eventually need reconstructive surgery to rebuild all the bone and muscle loss that Karl had from all of the radiation.

Karl then had the reconstructive surgery on December 22, 2005. This was over 16 hours of surgery where the fibula in his left leg was removed to create the bone structure of the left side of his face. Muscle and blood vessels were also taken from his leg. A "free flap" was built inside his mouth. Karl went through months of recovery where he could not eat solid foods, everything had to be blended and made into a soup-like structure. He was supposed to have the 2nd part of the reconstructive surgery in September of 2006, BC/BS would not pay for the titanium posts that Karl needed for future teeth. At that point he also started having limited movement of his mouth - he could not open his

mouth all of the way, but cancer was not suspected, it was thought it was part of the healing. By December of 2006 Karl was in extreme pain in his mouth and could barely eat anything.

So in January 2007 the 2nd phase of the reconstructive surgery was performed, even though BC/BS still hadn't approved the posts for teeth. The surgery itself went well; however, the surgeon was surprised to find that Karl's tongue was loaded with cancer, as was his soft pallet. We then consulted with Dr. Kerstin Stenson at the University of Chicago. Dr. Stenson performed her own biopsy and it was determined that Karl had squamous cell carcinoma. This is a cancer that is mainly from heavy smokers and or drinkers. Karl was never a smoker and only a social drinker. There was trouble getting surgery scheduled because of getting the right surgeons together, etc.

April 11, 2007 - Karl had 10-hours of surgery to remove his tongue, soft pallet, bone from his jaw and to do grafts from muscle from his leg to create a new tongue and skin from his leg to form the pallet and to graft behind his ear where bone was removed. He also had all of his lymph nodes removed from his neck. Karl was in the ICU for 4 days and required blood and constant care. He was given a trake because the airway was so constricted from the neck dissection. Karl came home in pretty bad shape. I took a 9-week leave from work to nurse him back. This consisted of cleaning the drains, flushing his IV line, cleaning the graft sites and medicating them and once every 1 hour suctioning out his trake. Karl was unable to sleep more than 15 minutes at a time because he was constantly choking. This went on for months.

October 3, 2007 - Karl beat the odds and returned to work as a laborer at The City of Palos Hills. He remained full-time until September 4, 2008 when we were given the news that the cancer was back - this time in his head.

Karl once again has squamous cell carcinoma - 2-ml's off the stem of his brain. This tumor is inoperable because of its location. Karl cannot have any more conventional radiation treatment as it will kill him. Chemotherapy alone will not work. Dr. Daniel Haraf, head of radiology at The University of Chicago informed us that Karl needed proton treatment. They then set us up with Dr. Allan Thornton of The Midwest Proton Radiotherapy Institute (MPRI) in Bloomington, IN. On September 26 we met with Dr. Thornton who was amazed of Karl's medical history and the fact that he was still alive from the first two cancers, let alone the new cancer. He agreed that proton treatment could give him a chance at life. He was given a 50% chance of survival with the proton treatment - 0% survival without it. Without the treatment Karl has approximately 1 year to live.

Our next nightmare began when Karl's surgery was not scheduled because BC/BS denied treatment. Karl's family came up with the \$80,000 down payment that was needed to start treatment - the other \$80,000 is due before treatment ends. We now have the money, but we don't have the neurosurgeon to perform the surgery that is needed before the treatment can begin.

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**Lastly a note from – Lena Pettus. Lena is a journalist writing a story about Karl and is looking to speak to anyone who has had proton therapy or a loved one who has had it.” Please drop Lena an email at [lenapettus@yahoo.com](mailto:lenapettus@yahoo.com) if you have any information on Proton Therapy.**

***PLEASE contact Nadine's sister at [fightersforkarl@yahoo.com](mailto:fightersforkarl@yahoo.com)***

**and ask her to add you to the list.**

