

## "Please Help Us Save Our Daughter. It's Truly A Matter Of Life Or Death."

Grace Cummings, a Madison teenager, needs a liver transplant. A portion of a healthy person's liver can replace another person's diseased liver. Then the donor liver grows back. Will you get tested to see if you can help Grace?



By Pem McNerney

**Editor's Note: Thank you to the Patch Community for your overwhelming support of the Cummings family as they go through this difficult time. Your response has been so generous that the family is asking that they and the Yale Transplant Center be given time to sort through the massive number of offers that have been made.**

Here is a note they sent us Thursday night, May 17th:

A Message from the Cummings Family;

"Many thanks from our family for the wonderful messages, prayers and actions taken by so many in response to Grace's transplant letter.

We have talked to the Yale Transplant Center and so many people have responded to our plea, Yale now needs time to further process the individuals that have been in touch with them to date.

As of right now, we are hopeful that a suitable donor can be found. Please do not contact the Yale Transplant Center and hold off on distributing the letter at this time. We will keep you posted to what's going on in the process as things can change daily."

Once again many thanks,  
George and Colleen Cummings

\*\*\*\*\*

**Original story posted Wednesday, May 16th:**

If you live in Madison, or know someone who lives in Madison, or know someone who knows someone who lives in Madison, chances are you may have received an email recently (or five) about a young girl in Madison who needs a liver transplant.

Members of the community are working hard to spread the word because Grace Cummings needs a transplant now and a donor must be found. Her parents are asking people to contact The Yale Transplant Referral Line Coordinator to see if they might be eligible to become a donor.

This initial call can simply serve as a fact-finding mission with no obligation, or can be an initial screening. Yale will protect the confidentiality and anonymity of all perspective donors. It is important to note that potential donors be between 18-55 years of age, are in good health and have a healthy lifestyle, have blood type O, no history of blood clots and other autoimmune diseases, have a BMI<28, and have active health insurance. Please help us help our daughter. It is truly a matter of life or death.

Thank you, George & Colleen Cummings

**Here is the full text of their plea. Send this out to everyone you know. Post it on community bulletin boards. Then, if you meet the medical requirements, make that call to Yale and see if you can help.**

It is with fear and trepidation that we write this email. Our daughter, Grace, is listed on the national liver transplant list, but is getting sicker and sicker each and every day. She needs a liver transplant. We are on a desperate mission to find her a live liver donor. Medical science has developed the procedure in which a portion of one person's healthy liver can replace another person's diseased liver and both donor and recipient can lead normal lives. The liver is an amazing organ and both sections will quickly grow to full size and functionality. Please help us in getting the word out to your family, friends and colleagues. We know that there are amazing people out there as we have had several people come forward but who are ineligible at this time.

When Grace was born in May, 1997, she was born with a choledochal cyst in the biliary tract of her liver. At 12 days old she had extensive liver surgery to remove the cyst, gall bladder and reroute parts of her intestines. She was closely monitored by the excellent staff at Connecticut Children's Medical Center (CCMC) taking daily medications and she was in good health until her second birthday (1999) when she developed her first bout of cholangitis, a bacterial infection in her liver. This was treated by a two week hospital stay on an IV of triple antibiotics.

After this episode, Grace continued with her normal activities in school and sports, and her passion for helping the American Liver Foundation. She started a team with her sister Meghan called "Captain Grace and Her Buccaneers" and had a large number of walkers. They collected \$36,000 for liver research over the last 10 years. She also made two TV Public Service Announcements for the ALF and was chairperson of the walk on two different occasions. Unfortunately, in 2010, cholangitis came roaring back into her life. She had episodes in April 2010, March 2011, June 2011, and December 2011. Each time, hospital stays of 5-7 days were needed and she came out with a PICC line for IV antibiotics to be administered at home for 30 days.

Obviously, this cut into her school time and activities. Liver diseases are sneaky. Sufferers can appear normal while the disease erodes the liver and biliary tracts causing stress and damage to associated parts of the body. During these years, Grace was able to live an apparently normal life, although recently, fatigue and itching have started to sap her energies. From the Choledochal Cyst and removal, and episodes of cholangitis, Grace presented with a new disease, Sclerosing Cholangitis. She also has evidence of Portal Hypertension and Cirrhosis. She is now being treated by Dr. Pramod Mistry, Pediatric Hepatologist at Yale University and Dr. Sukru Emre, Head of Surgery at Yale Transplantation Center.

The doctors told us Grace needs a new liver now. Cadaver liver allocations are based on a ranking called the MELD (Model End Stage Liver Disease) score. Choledochal cysts and Sclerosing Cholangitis do not mesh well with this standardized system. Although she is quite ill, her MELD score remains low. Doctors told us that by the time her MELD score is high enough to qualify for a cadaver liver, she will be within 72 hours of death. Grace needs a live donor liver transplant now.

We need your help in this next leg of our journey. Please forward this email. We have to get the word out. Our insurance will cover all expenses for being tested, the transplant surgery and recovery time for up to 3 months.

To find out more about being a living donor, individuals can call The Yale Transplant Referral Line Coordinator at 1-866-925-3897. This initial call can simply serve as a fact-finding mission with no obligation, or can be an initial screening. Yale will protect the confidentiality and anonymity of all perspective donors. It is important to note that potential donors be between 18-55 years of age, are in good health and have a healthy lifestyle, have blood type O, no history of blood clots and other autoimmune diseases, have a BMI<28, and have active health insurance. Please help us help our daughter. It is truly a matter of life or death.

Thank you, George & Colleen Cummings

Grace Cummings Graduated Walter C. Polson Middle School (8th grade) 2011  
Parents: George and Colleen Cummings

Choledochal cyst and surgery to remove May 1997 Cholangitis May 1999, May 2010, April 2011, June 1011 and December 2011

Diagnosis: Evidence of Cirrhosis and Portal Hypertension (continued to develop slowly throughout the years).

Medications: Ursodiol, 300mg, 3/day Bactrim Superdose antibiotic, 1/day Prevacid, 30mg 3/wk Zinc, 25mg 1/day Multivitamin, 1/day Hydroxyzine Hcl, 25mg, up to 3/day as needed.

### Anonymous Thoughts About Grace From Friends:

"Grace is a very special young lady who has been involved in all kinds of youth activities since she was a kid and still remains extremely active today. Her unique personality always shows a positive presence and she prides herself in always making others happy and smiling. As sick as she is, she always puts others in front of herself and makes them feel on top of the world. Her friendship is truly a blessing and simply lights up our lives!"

"...many families can relate to your situation. However, there is one key difference that sets you apart from the rest. That difference is Grace. She has been through everything. It seems that there is nothing in this whole world that she could not outride with her indomitable spirits. As we know, the time has come when Grace needs our help. She is not facing this alone though. She inspires all of us. One time the team was doing hockey sprints at practice. We were all exhausted and on our last sprint, I looked over and saw that Grace was skating next to me. It was obvious that she was tired, as was I, but I saw her put her head down, dig deep and finish. Sometimes I am tired, and I feel like I can't keep going. When this happens, I think of that time on the ice, put my head down and finish what I have started."

"Grace does not just live; she excels in everything that she does. Grace is a champion in school, in the community and in sports--on the field, ice rink and tennis court. Along with her family, she has been a relentless supporter of the American Liver Foundation, dedicating her time and talents to the pursuit of cures for all types of liver diseases. In Grace's world, it's not all about Grace, rather all about family, friendship and community. Grace approaches all that she does with a keen intellect, kind heart and generous nature. She wears a smile even when she's hurting from a sports injury or a medical procedure. When I think of Grace, the words 'true grit' come to mind."

"In Grace's world, there is no word for quitting. She's a champ, a winner, using all of her gifts everyday in every way. Her illness does not define her nor dampen her dreams. Her illness is a burden that she bears with a spirit and wisdom beyond her years. She knows she has liver disease; yet, she knows what she has to give and gives generously."

"You'll know Grace by her smile and her passion for life. She inspires just being Grace!"

### Comments on the Madison Patch website about the story:

Comments+ [Leave a Comment](#)



[Scott Wilson](#) May 16, 2012 at 01:55 PM

Grace, I called and left my name for the nurse to contact me. I am O negative but my BMI is a little high. I don't know if they will test me. People, I know a husband and wife who did this and they are both alive and healthy. If you do anything in your life, the most important is helping another person. Please call and get tested. One of our neighbors needs us. Scott W.

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[Ann Cosma](#) May 16, 2012 at 05:17 PM

I wish I was O negative, but I am not. I will keep you in my thoughts and pass around this notice. Annie (Hand High Class of 93)

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[Cinda](#) May 16, 2012 at 05:46 PM

I left a message to donate Cinda

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[Cathy Marsh](#) May 16, 2012 at 06:24 PM

There are 4 people manning the phones on this referral line at Yale. They will get back to you if you leave a message. There is also a Answering Machine Service that sometimes takes messages. It seems safest to contact them during business hours.

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[Gail Benson](#) May 17, 2012 at 12:29 AM

I'm sorry I don't have type O blood, and I am in my 60's. I will keep praying for a liver for you.

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Ann Nyberg May 17, 2012 at 01:23 AM

I am type O negative, the universal donor, how can I help?

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Rebecca Gordon May 17, 2012 at 01:43 AM

I'm O neg. I'll call tomorrow.

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Lynne McHale May 17, 2012 at 01:50 AM

I am the Outreach Coordinator. Please feel free to contact me with any questions about Living Donation. E-mail me at Lynne.McHale@ynhh.org. Thank you, Lynne McHale, RN, CCTC

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Brad Shwidock May 17, 2012 at 02:01 AM

I have Sclerosing Cholangitis and received a portion of my wife's liver 8 months ago. We are both doing fine. To anyone out there thinking about donating you should know my wife did fantastic after the surgery. She donated 60% of her liver to me and most of her liver had regrown back within 3 months. It's a beautiful thing to give the gift of life. Please consider it for Grace.

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Linda May 17, 2012 at 02:11 AM

I so wish I could help Grace but I don't fit the parameters. I will continue to share your story though to help find a donor.

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Ron Roppo May 17, 2012 at 02:18 AM

I'm 65 and in fair health I am " A " Positive if I can help count me in. roppo32640@att.net

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Natalie May 17, 2012 at 03:01 AM

I don't qualify do to not being type O, and my BMI is too high. I did post on my Facebook page though. You are all in my prayers.

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Sean Langrieger May 17, 2012 at 04:27 AM

I hope I can qualify. If I do not I will be looking for other people that will help the cause! We will find a way through this, we are all behind you Grace :-) stay strong !

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paula chisholm May 17, 2012 at 11:26 AM

I will be calling yale this morning..I am O positive a very healthy 60 yr old female and in good heath, live in Clinton and willing to help. I also have good insurance. I lost my brother last dec. to liver disease

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Debora Dunn May 17, 2012 at 12:43 PM

To Grace and her family, Madison is a beautiful community that comes together in the time of need. I personally experienced this when my daughter at the age of 15 months was diagnosed with leukemia. My little girl is now 7. I will pray for you all. Have HOPE.

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Janet D. May 17, 2012 at 12:44 PM

Hi Ann, If there was a way to publicize this through WTNH, we could reach so many people. What can I do to help you with that? Is there any information you would need? I am in contact with Grace's mom and want to help as much as I can. You are a great resource. Janet Dielman

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Brian Young May 17, 2012 at 12:57 PM

I am "O" positive and will be calling. Also, I work for the American Red Cross here in Ct. and run community blood drives on the shoreline. We could dedicate a drive in the area and help get the word out to the community. Peolpe who donate blood do it to help save lives! Just a thought. Brian brian.young@redcross.org

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Pem McNerney May 17, 2012 at 01:57 PM

Thanks to everyone who has helped so far by spreading the word and signing up to get tested. Let's keep it up! If anyone who is going to get tested is willing to have me tag along, maybe we could do a story about what it's like to do that. Let me know if you're willing.

pem.mcnerney@patch.com. Thanks again.



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Lori Lodge May 17, 2012 at 02:40 PM

Colleen & family - please know that you are in my thoughts. If my blood type was O I would be tested in a minute. Will keep asking people I know and pray that someone test positive as a match soon.

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SMI May 17, 2012 at 02:44 PM

Guilford is here for you too! We are sending out through sports websites, emails and word of mouth. Since my blood type is B positive, I can only help through a B positive attitude and getting the word out to as many people as I know. You have my prayers. We'll find someone! Emailed some people in Clinton and Branford as well. We may battle it out in sports but this is when we unite for a kid who needs help. God bless.

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Gary Greenstein May 17, 2012 at 03:56 PM

Our hearts go out to the family and to Grace. We moved to CT from Barrington, RI years ago where we have dear friends that are in a similar situation with their daughter who is desperately in search of a bone marrow match to help her fight with cancer. It is so important for people to understand the urgency of finding a donor in time. I am O positive and have contacted YNHH to volunteer as a donor! In addition, we own a store in Madison and want to do something to help as a member of the community. Please let us know what else we can do and how we can help. Call 203-245-0348...ask for Gary. We will spread the word....

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Gary Greenstein May 17, 2012 at 03:59 PM

Lynne, Can someone who is O positive be considered as a donor if they are in perfect health by over 55. Please respond.

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David Gagnon May 17, 2012 at 04:22 PM

I can't imagine what you and your family are going thru. Family and health are the most important things in life. Everything else can be replaced. I have 3 teenage children and they mean the world to me. I would only hope that if they were in a situation of need that someone would come to their aid. I just called Yale to determine if I would be a donor candidate. They indicated that someone will be in touch with me soon. Grace, God Bless you and your family during this challenging time.

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Alex England May 17, 2012 at 07:11 PM

I am O negative, 19 years old, my bmi is about 25, I am in good health, exercise daily and I have no history of health problems or blood clots. I have left a message at Yale and I hope I can be of help. Stay strong Grace!

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Andrew Elder May 17, 2012 at 10:55 PM

Just left my info with the answering service for the office! Should be getting a call tomorrow. I'm O Positive, 37, good health and BMI. Only concern is that I've been through pretty hefty chemotherapy - I've been turned down by both the bone marrow donor network, and can't donate blood for a few more years! But fingers are crossed!

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Andromahi (Mahi) Trivellas May 18, 2012 at 12:24 AM

I just called and hopefully will be hearing back tomorrow. 23, female, O+, BMI 21, yale grad, varsity lacrosse, very healthy! I donate blood all the time both at the red cross and MSK & HSS in NYC where I work.

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Elena Vezzetti May 18, 2012 at 01:58 AM

I will call tomorrow Yale tomorrow to get tested. I don't know my blood type, but, if it works, I am willing to help. Keep the faith, God answers prayers!

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Ann Della Camera May 18, 2012 at 02:03 AM

Grace, I also am O-negative, but my age it would do you no good, The one thing sweetie I can give you is my Prayers, and I see there are many much, much younger than I there to help you. Keep your chin up I know you will get someone. Prayer is strong and trust me many are praying for you now. Please keep me posted

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Ellen May 21, 2012 at 07:54 PM

Sending my thoughts and prayers to Grace and her family. Yale is calling people who have left messages and I received a call today to answer brief questions. They were flooded with calls

and we need to keep the screening going until they find a match for Grace. Keep spreading the word.

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**Rochelle Bronit** May 22, 2012 at 01:52 PM

Lynne - I emailed you last week as well. I understand you are sorting through responses. Hope to hear from you soon.

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**Tiffany** May 29, 2012 at 08:25 PM

I see that Yale is going through so many offers right now so it seems I should not call, but I am O+, 34, healthy. My name is T. Hesser and since I am listed in the phone book, I will tell you my number is 860-349-2490. I will be happy to be screened if you just let me know what is the best way at this point based on the message about Yale being overwhelmed right now.

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