



08-01-2007

Dear Kim,

Anne and I and my wife, Liz, are stunned by the generosity of the WA Class of '72. And please believe me when I say that it takes a lot to stun us. In the years since my family has encountered our medical troubles, we have been lifted up by a host of friends, acquaintances, and outright strangers. But when a group of people separated for thirty-five years comes together for a common cause and that cause is my family, we are absolutely blown away. Thank you and everyone involved for your tremendous kindness. We will certainly put your gift to good use.

Please share this note with your class. I have attached a smattering (I'm pretty sure I picked up that word from Mr. Vaillant!) of items to give you a feel for what's going on with us. The first is an article entitled "Room for Joy" that I wrote to thank our church for giving us an accessible van eight years ago. I think it's still an accurate representation of some of our spiritual beliefs and is appropriate to share with you. Ya'll have reminded us (again) that in this very broken world, we have much to be thankful for, especially for so many kind, caring people like yourselves. You make us feel surrounded by love. The second item is a quick update on my family that I included in a recent fundraising letter for the MS Society. It includes a picture of us.

And here's a real quick summary of my last 35 years:

Graduated from Harvard in '79 with a degree in Economics – played hoops there but mostly “rode the pine” (8th man in a 7-man rotation). Started first “real” job at IBM in '81 in Greensboro. I met Liz in my first year there (talk about fringe benefits!). We got married in '85. Matt and Will were born in '90. Liz was diagnosed with MS in '91, boys with MD in '93. I took family leave for a couple of years, then went back to IBM for a year before making a career change. Two years at Chapel Hill and I was a brand new Occupational Therapist at 41. That enabled me to get paid (not a lot, but enough) just for playing with disabled kids at Gateway Education Center, part of the Guilford County School system; and it helped me greatly in taking care of my own family. I thoroughly enjoyed working there for 4 years but decided to stop working to home-school Matt and Will when they started their middle school years. That's been our arrangement for the last 4 years and it's working very well so we plan to continue for the rest of their lives (10 years?) if possible. We built an accessible home in '96 that meets our needs and we've put down some deep roots. We feel blessed to be surrounded by kind neighbors, friends, and our church community. My mother-in-law lives only 3 houses down the street (Wait a second! Lost my train of thought. I was talking about things for which I'm *grateful*, wasn't I? Actually, she's very helpful and we have learned to get along with each other.)

...And this community that surrounds us just keeps on growing. Just this past weekend, the WA Class of 1972 joined that community and we feel blessed that they are part of our lives.

I guess that catches you up to the present. But there's one more thing that I need to thank you for, Kim. That's for being unselfish enough to pass the ball to a tall, skinny freshman back in the 71-72 season.

With deep gratitude,
Alex James



Will, Liz, Alex, and Matt

Liz James Just Keeps on Smiling!

A quick update on everybody: Liz has had a very tough year. After trying a new therapy involving a series of spinal taps in November, all of her symptoms suddenly worsened. She's been in the hospital five times this year. She's now using a feeding tube for nutrition, has more difficulty speaking, and generally needs more help with everything. But through it all, her wonderful personality has remained intact and for that we are truly grateful.

Matt and Will just turned 17 and are staying pretty busy. They're both still into wrestling and hip-hop music. Mom just can't abide hip-hop and we don't play it at home so when she was in the hospital Matt and Will had several hip-hop parties to help "pass the time" ("I think Mom would want us to do this," Will rationalized!). Other than that, Matt and Will really missed Liz and I have tender memories of our visits to see her in the hospital. At each visit, they would carefully maneuver their wheelchairs around all the hospital equipment so that they could get close enough to hold Liz's hand. They're still very interested in girls, Will so much so that we keep a spreadsheet of girlfriends and dates so that he can spread himself around fairly. Matt has a more modest number of special ladies that he manages to keep up with in his head.

I think I'm doing a pretty good job of making sure that everyone's needs are met. I enjoy getting up with a clear sense of purpose everyday and have learned to accept lots of help from lots of great people. We have two wonderful new young ladies helping out with Matt and Will and have also hired someone to help Liz out in the afternoon. I've had to shift some of my time from the boys to Liz but so far she seems to be tolerating me pretty well!

Please continue to keep us all, especially Liz, in your thoughts and prayers. Know that we count you among our many blessings. Thank you for your support in so many ways.

Take care and many thanks,

Alex James

Room for Joy

This story is primarily one of gratitude, in both a specific and a general sense. Specifically, we want to express our thanks to the very generous people of Holy Trinity and the community whose contributions have made it possible for our family to purchase an accessible van to accommodate two wheelchairs and an electric scooter. We are simply overwhelmed by

such a gift and don't know how we can adequately convey our gratitude. In a general sense, this story is about gratitude as a way of life that we are learning with your help.

Before we go on, it occurs to us that Holy Trinity is a vibrant, growing parish and that many of you reading this may be asking yourselves, "Who are these people and why did the church give them a van?" We are Liz and Alex James, parents of 8-year-old twin boys, Matt and Will.

In 1991, Liz was diagnosed with multiple sclerosis. The disease lay relatively dormant for a couple of years but became more aggressive, robbing Liz of her energy and producing a variety of symptoms which forced her to quit working three years ago. We are thankful that Liz has many remaining capacities (my favorite of which is her ability to radiate joy!), but this very unpredictable disease looms over us like a thundercloud. We try not to look up but rather to focus straight ahead.

In 1993, Matt and Will were both diagnosed with Duchenne muscular dystrophy, a terminal and very predictable, muscle-wasting disease. They both have experienced the global developmental delays that are sometimes associated with this form of MD. Matt also has autism. They are happy, silly boys and we have thoroughly enjoyed each other and the relative freedom of the so-called honeymoon period of this disease during which mobility is not terribly compromised. They are just entering what is termed the transition period where they are beginning to rely on their wheelchairs occasionally.

In early 1998, a campaign was launched to raise money for a van. The response was very generous. The van was ordered last fall and the final modifications are being made to the van as we are writing this. We expect to have the van in time to head south for a spring vacation. While we obviously wish we had no need for this vehicle, we are very happy and relieved that it will soon be here. We think the timing is just right as Matt and Will are still primarily walking and can simply enjoy the new van for a while rather than associating it with their increasing disability.

To be honest, we felt uneasy about accepting such a large gift. We were both raised to be self-reliant, expecting that we would spend most of our lives working and taking care of our own needs. Our idea of community was limited to our extended family and just a few friends. We *had* become accustomed to being in the debt of others for smaller kindnesses such as occasional home-cooked meals. But it's a huge leap from a dinner to a fully equipped van. With a meal, you can thank the person, tell them how much you enjoyed it, and face them later with your head held high. Accepting a van is a much more humbling experience. There's almost a knee-jerk reaction of shame. And there's guilt in knowing that there are others more in need than we. We don't even know who to thank individually. But we know that people throughout Holy Trinity and all over the community of Greensboro have helped us. Thank you all.

So how did we get past this? First, a good friend helped us identify these feelings as just another type of pride. If we truly believe that we've handed the medical problems and our whole lives over to God, shouldn't that include the pride, too? Second, you all continue to overwhelm us with kindness. There is now an organized team of "JoyFriends" (complete with bumper stickers) bringing us meals three times a week. Matt and Will have an inspirational song, professionally written and recorded just for them. You choose to see Matt's and Will's strengths while overlooking their idiosyncracies (this probably applies to us as well!). And most of all, there are the countless ways that you let us know daily that you care. Our community of faith is a tremendous source of strength and renewal for us. You nurture us in so many ways.

Now where is God in all of this? We feel surrounded by His love because we see His presence in all of you. You have helped us find joy in the midst of our pain. Every kindness we are shown is so appreciated and heartfelt because we are in pain. We no longer hold any illusion that we can do anything without each other and a community of faith. We have no idea what's going on and every illusion that we ever had of being self-sufficient or feeling that "We're doing just fine on our own, thank you" has evaporated. And yet, and this is the real paradox, we are being freed from all the things that used to tie us down. We are freer because we only care about a very few things. And now there is so much more room for joy. We have been blessed as we are surrounded by the love and support of so many people. It has made for a very rich life because we know that we need God and we know that we need each other. All of us need each other, regardless of what our culture is telling us.

Monday's (Feb. 22) Forward Day by Day really struck a chord with us, "...They needed someone who simply listened. Nothing changed for them: not their child, not the diagnosis, not their future. Yet it was marvelous, because for a moment we had beaten back the darkness that engulfed them, by being present for one another." You are always present for us. We hope this message serves as a means of our being present for you. Please know that we remain ever grateful. Thank you.