

## **In Our Mouths, Our Hearts, and Our Marrow: In Anticipation of the Yom Kippur Gift of Life Bone Marrow Donor Registry Drive**

Nitzavim-Vayelech September 19, 2014/24 Elul 5774

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[Trigger warning. This d'var Torah includes a discussion of blood and bone marrow donation and cancer.]

Fourteen years ago at roughly this time of year a group of four-year-olds, Rafi Samuels-Schwartz – my *madrich*, or teaching assistant – and I sat on a cozy blanket in the sun outside our Pre-K classroom. We huddled around a riddle raised by one of the students: Why does God need people? After some deliberating, one child suggested, “Maybe there are things we can do that God can’t do.” Other kids nodded, not troubled by the potential insecurity of a God who couldn’t do everything by God’s-Self. “What if we help God do the stuff that needs, well . . . you know . . . hands?” “What if we’re pretty much God’s action heroes?” “Hey!” Exclaimed another child. “Amy, look at you and Rafi! You even have capes! Maybe we are secretly superheroes!”

Anyone who knows me would know that of course I encouraged that conversation about our *tallitot*-wrapped selves being God’s costumed crusaders; God’s wizards, Nephilim or Shadowhunters. We might have our alter ego identities that make us appear ordinary, but really we are not normals, muggles, or mundanes and when we become adults in our community we even get to start wearing a cape to prove it.

Roughly a decade later in December 2010 I was diagnosed with AML – Acute Myelogenous Leukemia. After several rounds of chemo, On May 12, 2011 I had a bone marrow transplant from an unrelated, unknown adult male donor which means there is a (not Jewish) guy alive and walking around today in Germany whose bone marrow made the marrow in my bones and whose marrow in my bones is making my blood. That means I have two sets of DNA – the DNA in my tissues I was born with, and the DNA in my blood I received in my transplant. Weird and cool right? And life-saving.

On Yom Kippur, Mount Zion is joining over 72 congregations and the Union for Reform Judaism, the Religious Action Center, and Gift of Life<sup>1</sup> – a companion organization with Be the Match<sup>2</sup> – and hosting a bone marrow and stem cell registry drive giving our community an opportunity to join the registry or support others in joining.<sup>3</sup>

Because of my transplant, today I’m alive and cancer-free. My blood counts are excellent – I know because they are still tested regularly. I struggle with graft-vs-host disease (GVHD) – the tension between the cells I was born with and my new cells - in my gut, joints, and membranes like my eyes and mouth. I’m working full-time in an office doing work I don’t love but like okay and it pays bills and provides health insurance. My knees are recovering from prednisone damage. I’m exploring new hobbies that work for my body. I have global neuropathy and the medication for it makes me sleepy. My major organs all work reliably. I have cataracts from the radiation. I love to garden. I’ve chosen to modify what I eat and cut out everything that increases my inflammation and pain: No wheat, corn, soy, added sugar and about a half-a-dozen other things. I have anxiety

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<sup>1</sup> <http://www.giftoflife.org/> Gift of Life is an associate donor registry of Be the Match - the National Marrow Donor Program (NMDP) - and an accredited registry by the World Marrow Donor Association (WMDA).

<sup>2</sup> [www.bethematch.org](http://www.bethematch.org) Be The Match® is a global leader in bone marrow transplantation. They conduct research to improve transplant outcomes provide support and resources for patients, and partner with a global network.

<sup>3</sup> <http://mzion.org/event/bone-marrow-donor-recruitment-drive/>

attacks and I'm in EMDR and talk therapy for PTSD – post traumatic stress disorder – from the medical traumas. I found a Yin Yoga class that feels good. My new immune system has traded allergies, I'm no longer allergic to milk, but now I am allergic to coconut and sunscreen. It's hard, every day. And I also have life . . . . . and on August 10<sup>th</sup> thanks to the miracles of love and the hard work of justice Liddy and I stood under a *chuppah* and got married.

People have called me a cancer warrior. I never wanted to be a warrior. Thanks to Siana Goodwin's suggestion, instead of thinking of my white cells as an army, for almost 4 years now I've thought of them as my goats, munching on the weeds, taking care of business. Me, I'm like Abraham: a shepherd.

People have also called me a hero. I don't want to be a hero. I am an ordinary person who does the best I can to do what I need to and maintain my sense of self through all of it, and I've been very lucky.

Part of my luck is being Jewish in no small part because Judaism provides some structure and direction when all hell breaks loose and because Judaism is portable. We can take it with us on camping trips and we can take it with us into cancer treatment.

The rhythms of cancer treatment are incredibly powerful. It would be easy for them to take over a life. The rhythms of Judaism are less externally forceful, but they are more powerful. From the first of the first 6 weeks of in-patient chemo in the hospital, we made Shabbat together. White sheet on the table for a table cloth, electric candles, grape juice from food service, challah delivered by a friend. We talked with the care providers: For Shabbat, unless there was an emergency, no medical decisions by us. No new medications or changes in medications. We read some Torah. Even the weeks when I was on so much dilaudid – a painkiller that should have its own *bracha* – I couldn't really stay awake Liddy read to me. We spent a lot of months wandering with the Israelites in the desert, and as we revisit those verses each year the weight of their journey still catches us in tears. We built relationships on *Shabbat*. We made *havdallah*, every week, with an electrically wired wax *havdallah* candle made by a friend's dad and we smelled the spices fervently praying that the sweetness of those hours would help carry us through the next week and find me still alive for the next *Shabbat*. Those hours helped me remember that I was a person first, and then a patient, and to insist that my care providers saw me that way, too.

During my first break in chemo, Liddy made me a *Tu B'Shevat seder*. Through Caring Community friends and strangers delivered food to us and drove me to appointments, fulfilling so many *mitzvot*. At Mount Zion's blood drive that spring people wrote me notes as they stood in line to donate blood fulfilling the *mitzvah* of not standing idly by the blood of their neighbor, and I received that year over 36 units of blood transfusions. A friend came and chanted the *megillah* for us on *Purim*. A Chai School graduate and then college student (now medical student) stayed home with me while Liddy and others celebrated Chai School and High School graduation. And on the night of my transplant, a procedure that for the recipient is a lot like receiving a blood transfusion with more attentive supervision and more medications, we studied some text from Genesis and learned about Abel's bloods – plural – crying out from the ground. My donor's blood was about to become plural, too.

Everyone there said a *misheberach* for me, we said a *misheberach* for my donor as he recovered from his surgical procedure – under anesthesia – to remove some of his marrow from his pelvic bone with a needle about 12 hours before. We spoke in gratitude about the courier from Be the Match who had flown to Germany and back carrying my new marrow. The nurses hooked me up with a line from the bag of marrow to

the port in my chest and gravity – old school - brought those cells into my body. And then I slept. And we waited. We waited for many days, weeks, for those cells to find their way to my empty bones, to set up shop, to start making blood, and for my body to accept that blood. If it happened, I might live. If it didn't, I would surely die.

Tomorrow night with *Selichot*, and then throughout the High Holidays we will be praying, reading, and studying about life on the brink – who shall live, and who shall die. As a transplant recipient, I have an intimate experience with life on that ledge.

We don't talk much about death. The Torah doesn't, either. Rather curious because in the time of the Torah, the ancient Egyptians built tremendous buildings to defy death by creating something everlasting, pyramids that were giant mausoleums and even portals through which souls could join the immortals. A famous Egyptian text is *The Book of the Dead* intended to assist in the journey through the underworld and into the afterlife. In many ways the afterlife was more real than life, and life was a preparation for death.

In *Nitzavim-Vayelech*, our double *parsha* this week, Moses knew he was about to die. And yet, in his last words to us he didn't talk about what death is, or about what happens after we die. He talked about covenant, about choosing life, about teaching our children - which in our tradition includes our students - and about living well for ourselves and as an example for others.

We have a tradition of life after death, *olam haba*, the world to come. We also have *tehiyat hametim*, the resurrection of the dead, and references to resurrection which you'll see if you look for them in *mishkan t'fillah* during the Amidah. Tonight when we recite the *kaddish* for those who have died, we should look again at the words. Not one mention of death or the world to come.

And not only is there little talk of a world to come in the *Torah* or in prayer, it is also absent in other places we might expect to find it.

The book of Ecclesiastes is an extended lament of human mortality. *Havel havalim hakol havel*: Everything is worthless because life is a mere fleeting breath. Why did the author not mention life after death? In Job, a sustained protest about the injustice in the world, no one tells Job that he and other innocent people who suffer will be rewarded in the afterlife. Why not? Perhaps focus on afterlife could distract people from fighting against the injustices and evils in the world now.

In many ancient stories we get the cult of the hero whose immortality comes from killing, risking death, and personal aggrandizement.

Looking in the *parshiot* of these weeks leading up to and during the High Holidays for an immortal hero, Moses seems an obvious candidate, but Moses doesn't fit the paradigm.

In our days with Moses, we didn't have a pyramid or a temple, we had a *mishkan*, a portable sanctuary designed - not for the celebration of an important figure - but to create a space for God in our lives. We carried that *mishkan* with us and in it we carried our stories – stories like the binding of Isaac which we also read during the High Holidays. It's a challenging and troubling story in many ways, that must be said, but it is also the story not of the sacrifice of the person – Isaac – but of the binding of Isaac and then sacrifice of a ram, animal sacrifice. Animal sacrifice in the past was a central expression of connection with God, but our people came to transform that expression from animal sacrifice to prayer.

We are a people who does not rely on death or the threat of death to find meaning in life. We are taught in these *parshiot* that to find God we don't have to climb to heaven or cross the sea (Deut 30:12-13). We do not find God in a realm beyond life, in heaven, or after death. We find God in life. We find God in love and joy, two of the most-repeated concept words Deuteronomy. God is here. God is now. God IS life.

Liddy and I kept doing life together as we waited for my counts to climb.

And, *baruch HaShem*, they did.

I've called my donor a hero. After all he joined the registry and gave some of his marrow to a stranger. After my 2-year transplantaversary, and after we each signed releases, we exchanged some e-mail. I wrote him – one paragraph. He wrote me – three sentences. I wrote him – three sentences. Then . . . nothing. Friends of mine have joined the registry because everyone is someone's Amy. Maybe his friend is struggling with GVHD. Maybe his friend died. Maybe it was his brother, or sister, or a parent. Maybe he is just an ordinary guy who did the right thing for a stranger even though it was hard. Maybe staying in touch with me is too hard. Maybe he just doesn't want to.

I will always be grateful to him, and I don't need him to be a hero. Ordinary people can become dangerously ill. Ordinary people can die. Ordinary people, like my donor, like me, like you can also help save a life. Some of us can call something heroic and think, Yeah, I can totally see myself being a hero and doing that. After all, we're the tallit-cape-wearing superheroes God is waiting for. But then others of us might name something heroic, hear someone called a hero, call someone a hero and get caught in feeling like because we are not heroes we could never be part of life saving and then just do . . . nothing.

Judaism doesn't ask us to be heroes. Judaism asks us to be people. That's all the Yiddish word *mensch* means. It means human being. It means being the best self we're called to do *teshuvah* to get back in touch with, and it means making choices from our best selves.

Each day for the past 1,228 days, that is three years, four months, and nine days, I have thought about my marrow donor and the blood we share and at some point in the day almost every day I've had to make a choice for life – not always literal life-and-death life, but for life that is more than breathing.

In our *parshiot* God tells us, "See, . . . that I have set before you life and death, the blessing and the curse; therefore choose life." (Deut 30:15, 19)

How do we choose life and live as an example for the people who learn from us?

All of the people who support or participate in research about cancer treatment and bone marrow or stem cell transplant or donate money to organizations or join the registry choose life. Blood donors choose life when they donate and volunteers choose life when they make *matzah ball* soup or serve orange juice to donors. We could choose life by supporting the Mount Zion Yom Kippur Gift of Life registry drive, by helping get the word out, by learning about the process, by making a financial donation, by volunteering, or by joining the registry.

But what if talk of blood and cancer and bone marrow is too much for us or just not our thing? *Nitzavim-Vayelech* and Moses - our great, ordinary, human leader who achieved immortality by making us his students - are here to help.

“For this commandment which I command you this day, is not concealed from you, nor is it far away. It is not in heaven that you should say, Who will go up to heaven for us and fetch it for us, to tell it to us, so that we can fulfill it? . . . Rather this thing is very close to you, it is in your mouth and in your heart.”

As my preschoolers figured out, God needs our hands, and we need each other’s hands. We need to keep bringing Judaism with us. We need to keep doing *teshuvah* and returning to our best, wonderful, and wonderfully ordinary selves and acting so that others can become their best selves for having known us.

We could join with Mount Zion’s Caring Community<sup>4</sup> and help each other with rides and meals and dog walking. We could be the person who says . . . something . . . when we hear racist remarks. We could think more than twice about what we buy and the impact of the purchase. We could grow bee and butterfly-friendly gardens. We could muster the courage to face our own privilege and work to figure out how to use it to help heal the world or amplify someone else’s voice. We could talk, really talk, about mental health, about child abuse, about rape culture. There is so much to do. We could each do something.

What about right now? Right here in this sanctuary.

For most of my life, I’ve prayed the *misheberach* for other people. Since December 2010 I’ve had the experience of having people pray for me. A lot of people.

There are some things I do not believe about God or prayer. I do not believe God is waiting for enough of us to pray tip a heavenly scale and heal someone. Only a God I could never believe in would be so cruel. I do not believe people die because God ignored our prayers. I do not believe I am cancer-free because people pray for me. I do not believe I have to believe in God for prayer to make a difference for me.

There may be things you do not believe, too.

Here’s what I do believe: I do believe that whether we call it prayer, or setting our intention before yoga, or meditating, or thinking thoughts toward something or someone – and whether we call it God, or energy, or the threads between people, or simply Something Bigger Than Us – there is something to directing some of our energy toward someone or something. I believe it can change me to engage in that, and for me when all of that energy or prayer is directed toward me it feels . . . well, like a trust activity. It feels like everyone praying is holding out a hand and I can lean into those hands and all together everyone can help hold the hard. Because of my health journey, I know a lot more sick and struggling people and I am a lot more aware of my own need to feel supported in caring for and about them. When I stand in community to recite the *misheberach*, I like having company in feeling sad or angry or scared or hopeful.

May we find the courage to make our lives a blessing, we are about to sing. May we have the courage to choose life. May we have the courage to be ordinary people. May we have the courage to be our best selves. May we pray or set our intention or give some of our energy to life and to lives and to a world with more wholeness and less hurt.

In a moment, Cantor Strauss-Klein will lead us on page 253 in the *misheberach*. I want to be sure that tonight, we really have time to think about the names in our hearts and in our mouths, maybe in our marrow. I invite

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<sup>4</sup> <http://mzion.org/caring-community/>

you to start thinking of those people now. Whose name does your heart want to reach out toward in your life, in our community, in other communities, or in the world? Maybe it's your own.

When I invite you to stand, if for any reason you cannot stand, of course please take care of yourself.

If there is someone in your family, including yourself, for whom your heart would like to pray the *misheberach* right now, please stand and as people stand say their name or names out loud.

If there is someone in your circle of friends and neighbors for whom your heart would like to pray the *misheberach* right now, please stand and as people stand say their name or names out loud.

If there is someone in our community for whom you would like to pray the *misheberach* right now, please stand and as people stand say their name or names out loud.

If there is someone in other communities, please stand and say those names.

If there is someone in the world, maybe you don't even know them by name, please stand together and say something that describes them.

If prayer isn't your thing, but now looking around you want to stand beside those standing and beside those exercising good self-care by sitting, please do and everyone please turn to page 253 for the *Misheberach*.

Amen. Shabbat Shalom. Shana Tovah.