



No *shadchan* in her right mind would have thought of matching me with my husband. He is an Orthodox-born Syrian Jew, and I, an Ashkenazic *ba'alat teshuvah*. But that unlikely match was made, bringing meaning, joy and countless blessings to my life.

Because my husband is Sephardic, our match came with an added benefit: it freed me from the severe test which my parents had to endure, and from which I'd now like to protect my children.

My parents were overjoyed with the birth of their first child, Sarah Jane. The baby seemed perfect. But as time passed, her development stopped and a reversal took over. She began losing the ability to turn over, sit or reach out.

Shortly after, Sarah Jane was diag-

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*Rose Esses is a pen name used to protect the author's children from possible discrimination. She hopes that with the institution of mass genetic screening for fatal diseases, such a concern will cease to be necessary.*

## CARRYING A HEAVY BURDEN

By Rose Esses

nosed with Tay-Sachs disease, which causes severe brain damage, enlargement of the head, blindness, deafness, and eventual death at three or four years old. This gorgeous child was destined to waste away. No longer responsive to a mother's touch, my sister died when she was one and a half years old.

With the diagnosis, my parents discovered that they were both carriers of the recessive Tay-Sachs gene (a necessary factor for a baby to be born with the disease). Like any two Tay-Sachs carriers, my parents had a one in four chance that a baby born to them would be so afflicted. My mother and father yearned for a child, and know-

ing the risk, decided to try again. The result was me, and I've been told I eased their fears slightly by reaching the milestones of that first year "on time."

Let me jump ahead a little. My daughter is now beginning to date. The way she is looking for her

husband, however, is quite different from the way that I met mine, and I suspect it is different from the way most Modern Orthodox couples of my generation found each other as well. The majority of us met by chance, and learned of each other's attributes and backgrounds over the course of time.

That will not be the case for many of our children. Committed to Jewish life, seeking all the right things, they are choosing a "new" mode of dating—being set up using intermediaries—but not in the totally traditional sense. Their "*shadchans*" are usually friends who arrange introductions and transmit

communication during the first few dates. Before the couples meet, the intermediaries ask all kinds of questions about them, and address the daters' concerns in great detail.

However, there is one major issue they overlook: genetic compatibility.

My Sephardic daughter is now meeting Ashkenazic boys. She's part of a large, well-educated *frum* college community. And suddenly my husband and I are filled with fear. We wanted her to get tested to see if she was a carrier of Tay-Sachs, (which, in fact, she is) and we assumed that her Ashkenazic friends would feel the same urgency that we did. But few of them give a thought to Tay-Sachs disease. None of her friends had ever been tested, and none knew that 1 out of 27 Jews of Ashkenazic descent<sup>1</sup> is a carrier. Nor are people who are aware of a familial history of the disease the only ones at risk of being carriers.

I asked my daughter—these are such smart kids—“When do they find out if they are carriers?” She answered, “When they're getting engaged.”

I think of my father who could not bear to mention or hear of his deceased baby; of my mother, forced to tell me their experience when I came of marriageable age, taking out the hidden envelope of photographs of their angel—hidden not for the shame, but for the pain.

The more traditional among us, who more actively screen their children's prospective dates, have been dealing with this issue already for many years. Chevra Dor Yesharim is an organization which routinely conducts genetic testing for these communities. It assigns anonymous numbers to its clients, and does not inform the individuals of the results. (A simple blood test can reveal if a person is a carrier of various genetic diseases.) The *shadchans* themselves will check the numbers of each party before introducing a couple. If both are carriers of a fatal disease, they won't be set up. It's just one of many factors of compatibility to consider.

Since 1986, two years after Chevra Dor Yesharim was founded, screening

has resulted in not one Tay-Sachs child being born to *Chareidi* couples in Israel.<sup>2</sup> Since its inception, Chevra Dor Yesharim claims to have tested over 70,000 people and to have identified over 100 at-risk couples, advising them to avoid such marriages.<sup>3</sup>

As it stands now, couples in the more modern community wait to be tested until they are emotionally invested in a relationship. Why should they be faced with the prospect of breaking up with the person they love? Alternatively, how can one bear to proceed with a marriage with a one in four chance of having a terminally ill child?

We need to take advantage of our ability to eliminate this death sentence.

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As parents we need to take the lead. Our children think they are invincible, that with their *bashert* they can overcome all obstacles. But this obstacle is preventable. We need to speak to our rabbis, principals and community leaders, and urge mass confidential<sup>4</sup> testing of our high school and college-age children, to determine who are carriers of fatal diseases such as Tay-Sachs.<sup>5</sup> Of course, we must ensure that no carrier is left with the misconception that he or she is either unhealthy or defective. Indeed, a carrier is most likely a healthy person who can safely marry anyone except another carrier. If such testing were initiated in our high schools and on our college campuses, with education and counseling available and confidentiality assured, concerns could be assuaged and tragedies

averted. Modern Orthodox youth who arrange introductions would be able to avoid inappropriate matches. Those who choose to date more randomly could make a phone call early in a relationship to check their "numbers" and assure compatibility.

We run awareness campaigns of all types in our schools and *shuls*. We organize rallies for thousands at a moment's notice. We introduce our kids to donating blood from when they are in high school. Why not offer genetic screening blood tests at the same time?

My parents went on to have a second child, my brother. They feared that they would “smother” me if I were left an only child. When they called us their miracles, we didn't realize how true it was.

I have confidence that our children, with Hashem's help, will be up to the tasks that challenge them, and I pray that they relish the joy of their own miracles. Let them not have to deal with heart-wrenching choices inflicted by our lack of guidance. **JA**

#### Notes:

1. National Tay-Sachs & Allied Diseases Association (NTSAD), New York Area, [www.ntsad.org/pages/t-sachs.htm](http://www.ntsad.org/pages/t-sachs.htm).
2. Robert J. Brooker, *Genetics: Analysis and Principles* (San Francisco: Benjamin Cummings, 1999), 629.
3. E. Broide et al., “Screening for Tay-Sachs Disease in the Ultra Orthodox Ashkenazi Jewish Community in Israel,” *American Jewish Human Genetics* 47(1993): 213-215.
4. Although we may want to know our results, confidentiality is an effective means of responding to many complicated questions that arise with regard to genetic screening: stigma that may be attached to carrier status by the uneducated, discrimination by employers or insurers etc. See the discussion in “Judaism, Genetic Screening and Genetic Therapy,” by Fred Rosner, M.D., Institute for Jewish Medical Ethics, [www.ijme.org](http://www.ijme.org).
5. I am aware of the complicated and continuing halachic and ethical questions which surround the issue of mass testing for *non* fatal genetic diseases. Extensive halachic discussions have, however, supported testing for fatal diseases.