

CENTRAL CONFERENCE OF AMERICAN RABBIS
NEWSLETTER ARTICLE
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As some of you may know, this past year, my son Sam was diagnosed with Familial Dysautonomia (FD). FD is a Jewish genetic disease that causes the autonomic and sensory nervous systems to malfunction. It is part of a panel of more than 18 diseases that Ashkenazi Jews should be screened for prior to starting a family. We were married by two rabbis, one Reform and one Conservative, and neither one of them told us about Jewish Genetic testing. When my wife became pregnant, she was screened through her obstetrician and was told, when the results came back, that everything was ok. We later found out he never read the report. Due to this diagnosis, our life has changed dramatically, and making sure Sam is as healthy as can be is an ongoing challenge. Thanks to Sam's therapists and Dr. Felicia Axelrod at the Dysautonomia Center at NYU Medical Center, Sam has a team of professionals dedicated to his well being. Several decades ago, Sam might have died before he reached his fifth birthday. Now, the prognosis is much better but what will happen in the future is largely unknown. With God's help, he will live a long and healthy life.

It has become a personal quest for me to educate our community, both locally and nationally, about the severity and impact of Jewish genetic diseases, and the need for counseling and screening. I feel that we, as religious leaders in the community, have a responsibility to make sure that our congregants are aware of this incredibly important information. Ideally, they should have this information before they start a family, which is the optimal time for screening.

I know there are many demands on our time but we cannot leave the protection and the future of the Jewish community to doctors alone. We have the power to help bring healthy children into our midst, ones who will lead the Jewish people for many generations to come. This is a Jewish issue and we must be proactive and vigilant in order to eradicate Jewish Genetic Diseases from our midst.

There is much we can do and this will become of priority for the CCAR. Right now, you can make a difference by:

- 1) Educate yourself about Jewish genetic diseases. There are several places to go to do this. I recommend the Jewish Genetic Disease Consortium (JGDC) in NY. Their website is <http://www.jewishgeneticdiseases.org>. You may also wish to contact the Victor Center for Jewish Genetic Diseases at Albert Einstein Medical Center in Philadelphia. Their website is <http://www.victorcenters.org> and it is also filled with useful information.
- 2) When meeting with wedding couples, please impress on them the importance of being screened. You can visit the National Society of Genetic Counselors website at NSGC.org for a listing of genetic counselors and screening centers nationwide. All counselors are accredited and are excellent resources for you and your couples. It is crucial that they meet with a genetic counselor before they are screened to explain the process and what will happen if they happen to be a carrier for one of the Jewish genetic diseases. Only one partner in the couple needs to be screened, as both parents have to be carriers in order for a child to be born with one.
- 3) Educate your local community about Jewish Genetic Diseases. This includes your synagogue community and the community at large.

With the High Holy Day season upon us, let us not have to say an additional *Al Chet* for the sin of failing to educate our communities about something so crucial as Jewish Genetic Diseases. For any given family in your congregation, it could mean be the difference the life and death of a child. Let this not be a sin we carry on our shoulders. Please feel free to contact me if you need any additional information.

L'Shana Tova u'Metukah.

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