

COEJL's Web site describes its three-pronged approach of “engaging the Jewish community in awareness, advocacy and concrete action to reduce greenhouse gas emissions and promote energy conservation and sustainable legislation,” in order to “change how American Jewry responds to ... daunting environmental problems.”

This all sounds good, but why, you may be wondering, is this a Jewish issue?

God said this to Adam: “See My works, how good and praiseworthy they are? And all that I have created, I made for you. [But] be mindful that you do not spoil and destroy My world — for if you spoil it, there is no one after you to repair it” (Midrash Kohelet Rabbah 7:13).

And, COEJL argues, Jewish values such as tikkun olam and tzedek should be extended to include not just people but other animals and plants.

OK, you've conceded. It is Jewish. But is this really about Chanukah?

Well, what about the Festival of Lights? About making resources last longer than we thought they could? Like for eight nights, perhaps?

High-efficiency lightbulbs actually last eight times longer than regular lightbulbs. Imagine that. And speaking of the number eight, see COEJL's list of eight actions in eight days as a simple and concrete way to bring some ecoconsciousness into your Chanukah holiday practice.

So, you might be left wondering, just how many Jews does it take to change a lightbulb? As many as possible. As of the writing of this article, more than 20,000 energy-efficient lightbulbs have been sold through COEJL, saving 8,250 tons of carbon dioxide from entering the atmosphere.

So, as you nosh on your latkes this Chanukah, be a modern-day Maccabee — take action against global warming and environmental degradation.

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Group hopes Gaucher becomes household name

BY Lorelei Laird (https://jewishjournal.com/author/lorelei_laird/) | PUBLISHED Nov 16, 2006 | Community Briefs

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When Michael Margolis was 4, his doctor took his parents aside and told them he had a rare disorder called Type I Gaucher Disease. The disease, which strikes Ashkenazi Jews seven times more often than the general population, is a genetic disorder that robs patients of an enzyme that prevents a buildup of fatty tissues in the body. Victims develop a swollen spleen and liver, anemia-related chronic fatigue and debilitating bone pain.

In severe cases, the patient's spleen sometimes swells so much that patient looks pregnant. Because the condition was considered incurable and untreatable until the early 1990s, Margolis and his family were told that all they could do was ignore it and hope for the best.

Doing so became harder as time went on. In their early 20s, Type I Gaucher (pronounced "go-shay") patients typically start to go through "bone crises," in which a buildup of fatty tissues blocks blood flow to the bones. The bones then die over a period of weeks in a gangrene-like process, leaving the patient in debilitating pain. Left untreated for a long time, patients develop weak skeletons and often need both hips replaced. They may also need their spleens removed to stop the progressively larger swelling of the organ that characterizes the disease.

All of that was happening to Margolis, who is 58 now and a television producer living in Valley Village. By 1991, when the FDA approved an enzyme replacement therapy for Type I Gaucher Disease he was only in his 40s, but he was looking at a future that included hip replacements, spleen removal and a weakened skeleton.

"If I had gone on without treatment ... I'd have been in pretty sad shape right now," Margolis, said recently. "I hate to see other people go through the same process needlessly."

Margolis is on a mission to make sure no one does. Inspired by the success of the early-1980s campaign to raise awareness of Tay-Sachs Disease, he formed the Jewish-Associated Disease Action Committee (JADAC) this spring. The organization's mission: To raise awareness in the Jewish community of Gaucher and other Jewish-associated genetic diseases, and to make them household names.

The committee's first strike came last spring, when Margolis, whose professional credits include the 1990s reality show, "Crusaders," used his professional chops as a TV producer to make an informational DVD about Gaucher Disease called, "A Message to Elijah." Narrated by Elliot Gould, the DVD introduces new Gaucher patients to three Los Angeles-area patients who are living active, full lives with the disease. It has already reached 7,000 people, Margolis said, and JADAC plans to produce such a DVD for every Jewish-associated genetic disease. They list 15 such diseases on their Web site (Two neighborhoods reveal Orthodox community's fault lines (<http://www.jadac.org> <view-source:http://www.jadac.org/> TARGET='_blank'>www.jadac.org), including four that primarily affect Sephardic Jews. </p><p> "Out of those ... genetic diseases, about one out of seven Jewish people carry one of the genes," Margolis said. "So it's something that affects every Jewish family."</p><p> Gaucher Disease is relatively unknown in the United States because of its rarity. Dr. Henry Mankin of the Massachusetts General Hospital, a member of the National Gaucher Foundation's medical board, estimates that only 30,000 to 40,000 Americans have the disease. In the general population, one in every 60,000 to 120,000 people are born with Type I Gaucher Disease. But it's much less rare among Jewish people of East European descent, who make up the majority of American Jews. The foundation says one of every 450 Ashkenazim is born with Gaucher Disease; one of every 14 carries the gene. (There are two other types of Gaucher Disease, neither of which is particularly common among Jewish people.)</p><p> Ashkenazi couples who both carry the gene have a one in four chance of having a child with the disease.</p><p> Despite the substantially increased risk for Gaucher in the Jewish community, Margolis said, Jewish people are often no more aware of it than any other group.</p><p> This exacerbates a common problem among Gaucher patients: being misdiagnosed, sometimes catastrophically so. Because their most common symptoms are often vague — bruising easily, bone pain, low counts of red blood cells and platelets, abdominal swelling — Gaucher patients may shuffle from specialist to specialist for years, or even begin treatments for diseases they don't have, before they discover the real problem.</p><p> Dr. Barry Rosenbloom of Tower Hematology Oncology Medical Group in Beverly Hills is a Gaucher Disease expert who sees patients from all over the Southwest. He said most of his patients have been diagnosed circuitously, often after having their spleens removed.</p><p> Doctors know about the disease, Rosenbloom said, but they may not think of diagnosing it if they don't happen to specialize in a related area of medicine. And even though two-thirds of Type I Gaucher patients are Ashkenazi Jewish, he said, he agrees that the disease is not well known in the Jewish community: "They've heard of it, [but] they're not really sure what it is."</p><p> That can stymie efforts to identify the disease early in the patient's life, the doctor said. That's exactly the kind of situation Margolis wants to stop.</p><p> "It's especially bad if you go through a bone crisis and you don't know what's causing it," he said. "[You're] in the middle of this debilitating pain and you don't know if it's ever going to go away, because you don't know what the problem is."</p><p> "If it's diagnosed very early, you ... end up not having any of those problems."</p><p> Margolis had found that previous efforts to raise awareness of Gaucher Disease in the Jewish community had not

always been effective, particularly in reaching more secular Jews. Because fewer than half of Jewish Americans are affiliated with a temple or a religious organization like Hadassah, they can't always be reached through the places where Jews congregate. For that reason, JADAC decided early on to use secular, lighthearted tactics in its awareness campaigns.

That was part of the idea behind JADAC's first annual Deli-Thon, held in September in 14 Los Angeles-area delis and featuring the world's largest corned beef sandwich. The goal was to raise awareness of Gaucher Disease, not money, in a setting that reached secular Jews and even non-Jews. Attendees were encouraged to call or e-mail at least five friends or family members with information about the disease; JADAC also placed informational cards on all the tables in the delis. In all, the organization estimates that it reached more than 28,000 people.

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