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Jewish group supports German breast cancer detection tool employing blind women

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The Medical Tactile Examiners (MTEs) use self-adhesive stripes with tactile orientation points to identify abnormalities in the breast.

BY ALINA DAIN SHARON,
JNS.org

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As of 2005, German gynecologist Dr. Frank Hoffmann was no longer allowed to send women under the age of 50 to get mammograms without first finding a breast abnormality during his routine examination. Since some breast lumps can be very small, Hoffmann wasn't certain he could discover something during the few minutes he had to spend with each patient. That's when he decided to launch an innovative program, Discovering Hands, hoping to give blind women an opportunity for a life-changing career

by turning their more acute sense of touch into a skilled breast tumor detection tool.

With 17 Medical Tactile Examiners (MTEs) already trained and working across Germany, Hoffmann's initiative has connected with the Ruderman Family Foundation, an organization based in Israel and Boston that prioritizes the inclusion of people with disabilities in the Jewish community. This partnership may enable Discovering Hands to branch out to Israel and the U.S.

"I don't know many examples of a Jewish and Israeli funder foundation investing in Germany. It's not easy with our history," Jay Ruderman, president of the Ruderman Family Foundation, told JNS.org.

Ruderman first met Hoffmann at a philanthropy conference in Switzerland. He then toured Germany with Hoffmann, examining the program in action at hospitals and clinics. With the support of various German governmental bodies and Hoffmann's 2010 election as fellow by ASHOKA, an organization that invests with social entrepreneurs, Hoffmann was able to develop an entire curriculum training blind and visually impaired women to become MTEs. The Ruderman foundation granted Discovering Hands an initial \$72,000 donation in 2013 to help it grow across Germany, and it will offer logistical support to bring the program to Israel, where initial discussions have taken place with the Hadassah University Hospital-Mt. Scopus in Jerusalem.

For women under the age of 40, mammograms are not always "very good at detecting tumors because the breast density is pretty high at that point and a lot of things are hidden," said Dr. Virginia Kaklamani, an oncologist at Chicago's Northwestern Memorial Hospital and associate professor of hematology-oncology at Northwestern University Feinberg School of Medicine, when asked about the potential of Discovering Hands.

But studies have shown that "if nurses are taught how to do self breast exams and they do them on themselves," then their exams are much more useful, Kaklamani told JNS.org. Therefore "the idea of having somebody trained to do breast exams, especially if because that individual... is visually impaired, [he or she] has a better sense of touch, I would think that would work."

In the MTE breast examination method, self-adhesive orientation stripes with tactile orientation points are attached to the patient's breast in various positions, and the breast is divided into zones that allow the examiners to define the precise square centimeter where an abnormality is found. Unlike an exam by a doctor, an MTE breast examination takes between 30 to 60 minutes.

Discovering Hands conducted a study in conjunction with the University of Essen, looking at 451 patients that were examined by MTEs. Among these patients, there were 32 abnormal findings that were discovered by the MTEs but not by the doctors. "Women with those findings would have been sent home by the doctors," Hoffmann told JNS.org. A new peer review study will begin in November.

"The results [of the Discovering Hands study] are very encouraging," Kaklamani said, cautioning that more studies are needed to test the program's full effectiveness.

"This technique can be seen to be complementary to mammograms, replacing the mammograms, or not at all beneficial if a woman has yearly mammograms. So all these are things that need to be taken into consideration," she said.

Hoffmann believes that that his program has potential beyond breast cancer detection. "A well-trained sense of touch is useful in other diagnostic situations... MTEs one day (could examine) the eye bulb, the prostate, the testicles" or lymph nodes, he said.

According to Kaklamani, breast cancer is notably prevalent in the Ashkenazi Jewish community because individuals of that ancestry can carry BRCA gene mutations. "In the general population one in 500 individuals are positive and in the Ashkenazi Jewish population it's one in 40.... BRCA mutations predispose significantly for breast cancer. So from that standpoint there's an increased incidence," she said.

Given its focus on the inclusion of people with disabilities, what sparked the Ruderman Family Foundation's interest in Discovering Hands is less the science behind breast cancer detection and more the program's potential to employ visually impaired women.

"I think [Discovering Hands] has a huge medical benefit for the community, but it also has a huge benefit for providing employment and inclusion for blind women," Jay Ruderman said.

Currently in Germany, training to become an MTE lasts nine months and takes place through vocational centers for the blind and visually impaired across Germany. Of the eight such centers in Germany, four are now qualified to train MTEs.

"Losing your sight means that you retract yourself from public life, lose contact with your friends, lose your job. Many of them are reduced to the four walls of their own home," Hoffmann said. "Taking part in aspects of other lives...connects them intensively with patients. On the other hand, doing their job, they are real life savers."

In addition to learning anatomy and breast examination technique, women through Discovering Hands also learn communication and Braille technology skills so that "they can do their documentation on their own [and] don't need another helping person with them when they are doing their job," Hoffmann said. After six months of study and a final examination, the women undertake a three-month internship at a clinic.

According to Kim Charlson, director of the Perkins Braille & Talking Book Library at the Perkins School for the Blind in Watertown, Mass., one challenge blind people discover when searching for employment is "the attitude of people who are sighted about the abilities of people who are blind." She said some people think, "How could I do this job if I were blind? I couldn't; therefore, the person must not be able to do that job."

"The women in this program are absolutely going to have that extra skillset because they know how to interpret what they detecting with their fingers, whether it's Braille or if they're looking for a tumor," Charlson, who is blind herself, told JNS.org. "It's a great opportunity to work in that kind of healthcare field where blind people can make a significant contribution in some way, and have a job, and pay taxes, and do all those things like everybody else does."

Charlson, who is also a breast cancer survivor, is acutely aware of the challenges surrounding its diagnosis and treatment.

"I've gone through treatment, and early detection was critical for me," she said. "We should use all the tools that are out there."

In October, Discovering Hands started another training course in Nuremberg for the next four MTEs, and next spring another course will begin in Berlin and Halle, training six more. But women who want to be screened do not necessarily know this program exists, Hoffmann said. Insurance companies need to be willing to pay for these exams so that doctors will be willing to offer them in their clinics. In Germany, six insurance companies are paying for this examination.

Since medical, governmental, and insurance systems vary significantly from country to country, Hoffmann wants his program to expand outside of Germany as a social franchise model. All the documentations and plans behind the program can be given to private or governmental entities, which can use that information to implement the program independently in their own countries.

Discovering Hands is already working with partners to implement the program in nearby Austria by the end of next year.

For the Ruderman Family Foundation, the next step is to try to bring Discovering Hands to Israel by 2014, Jay Ruderman said. If the foundation can bring the program to a hospital and make it a success, the project may get some public attention and induce demand, and then the Israeli government might respond with funding and other assistance, he said.

"That's what I'm hoping will happen in Israel," Ruderman said.

The foundation is also open to helping bring the program to the U.S., where "most centers of Jewish gathering are not inclusive" to people with disabilities, Ruderman said. Of the entire U.S. population, about 17-18 percent have disabilities. In the U.S., the implementation of Discovering Hands could begin in Boston, according to Ruderman.

"I do think that this technology could be influential all around the world. You have to think of all the countries in the world where [mammograms are] either not available or extremely expensive. This is a very low-tech, brilliant idea that could be replicated all over

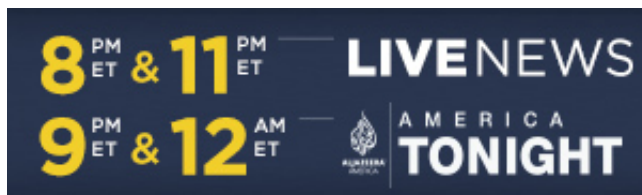
the world," Ruderman said.

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