

# THE EMPOWERED PA

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How Online Tools  
Are Changing  
Searches for  
Transplant Matches

BY LAURA FUSCO

A person is sitting on a grassy lawn, with their legs visible. A silver laptop is open in front of them. The back of the laptop lid is visible, featuring the word "PATIENT" in large, bold, green capital letters. The background is a soft-focus green lawn and trees under a bright sky. In the top right corner of the page, there are three vertical white bars of varying heights.

**PATIENT**

As consumers, we can search online for cars or real estate we may like to buy. We can even search online for a potential date or lifelong partner by checking a few boxes about our preferences in hair color, height and personality. So, as health care consumers in the 21st century, it is only natural that we should be able to identify our options in patient care with a few clicks of the mouse.

The cellular therapies community is one of the latest participants to join the consumer empowerment movement, as all of health care gradually evolves toward a patient-centered model. While professional search coordinators at U.S. transplant centers have had access to online search capabilities for years, only recently have patients had the option of searching for potential matches among publicly registered cord blood units and bone marrow donors.

At the center of this trend are new online tools that enable individuals facing illness to be active participants in their own care. These free Web resources — particularly those hosted by the New York Blood Center's National Cord Blood Program, the National Marrow Donor Program and the Gift of Life Bone Marrow Foundation — provide information designed to focus on a patient's individual needs, and are intended to better inform discussion with his or her physician.

## Cellular Therapy Tools For Patients

While there are some differentiating variables, all three of these online match applications enable patients to identify preliminary information on how many potential unrelated donors and cord blood units may be available to them at the time of their search. None of these patient-focused tools can be used to launch an official search, but rather provide results that will help facilitate discussion about whether an allogeneic bone marrow or cord blood transplant is a treatment option.

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Depending on the specific product, current models allow patients to enter low-, intermediate- or high-resolution HLA typing results available in their lab reports. After users read and/or “sign” disclaimer statements describing the limitations of the system, the search engine immediately returns the number of potential “matching” cord blood units and/or bone marrow donors listed in one or more registries. Each number returned is qualified by the number of HLA markers (out of six) that unit or donor shares with the patient.

NMDP maintains three contracts under the C.W. Bill Young Cell Transplantation Program, one of which is to provide patient advocacy and the single point of access for the public, patient services and transplant services. To help fulfill the single point of

access mandate, NMDP launched the search tool MatchView, which went live in May 2007 after nearly a year of development and usability testing. “The system does not share any donor-identifiable information when a patient requests a summary of potential matches,” explained Elizabeth Murphy, director of the Office of Patient Advocacy at the National Marrow Donor Program in Minneapolis, Minn., “it just says ‘you have potentially X number of six-out-of-six matches, and potentially X number of five-out-of-six matches, and so forth.’”

The Web site of NYBC’s National Cord Blood Program features a public cord blood unit search tool, which was launched six years ago at the recommendation of NYBC’s Pablo Rubinstein, MD, and Cladd Stevens, MD, in cooperation with a former patient. “We were collaborating on our program’s Web site with an individual who was a former patient, a cord blood recipient, and he had done a lot of work advocating for patients who needed to get access to the system,” said Machi Scaradavou, MD, medical director for the National Cord Blood Program, referring to the online database used by transplant search coordinators. “We agreed that patients should have some access to this system, so we developed this idea. It was a good idea.”

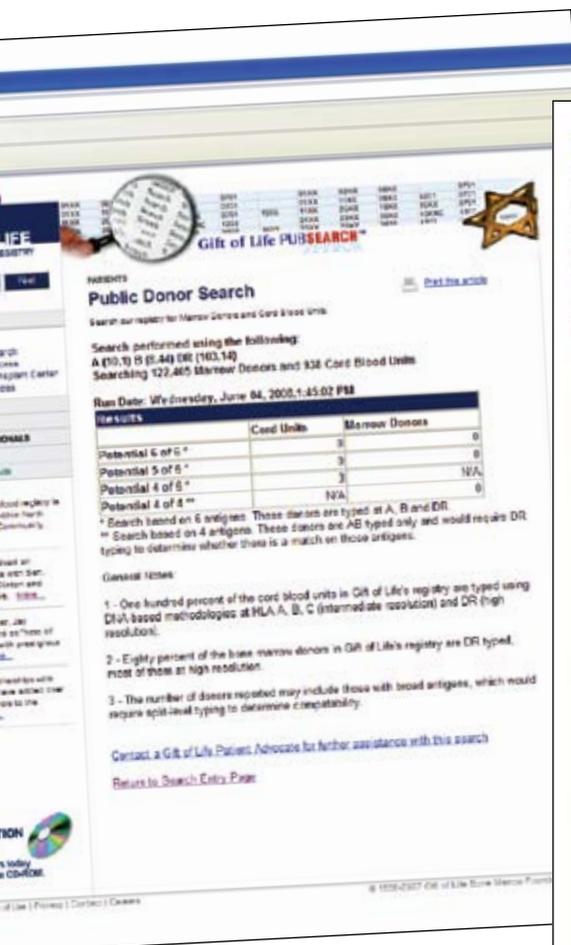
Jay Feinberg, executive director of the Gift of Life Bone Marrow Foundation, based in Boca Raton, Fla., knows better than most how important it is for patients to be informed of the possibilities for their own cellular and biological therapies. Diagnosed in 1991 with chronic myeloid leukemia, he spent four years waiting for an unrelated bone marrow donor to be identified.

“I was told the reason for the wait was because of my ethnic background,” Feinberg said. “The international donor pool at the time underrepresented most racial and ethnic minorities, so my family and I decided that we would be pro-active and do bone marrow recruitment drives in the Jewish community.” In 1995, Feinberg launched Gift of Life to help other patients like him. The online “PubSearch” application of Gift of Life went live in fall 2007.

### Searchable Inventories

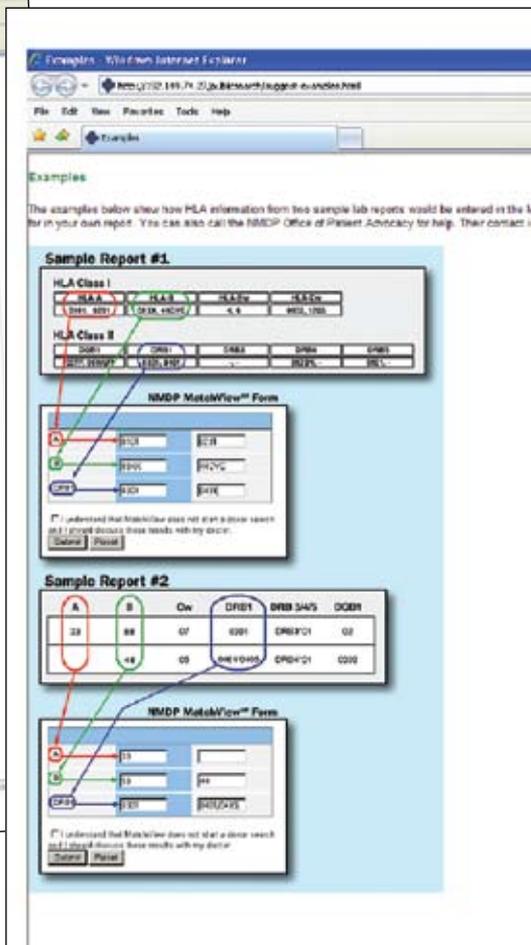
All three registries have a common goal — patient advocacy and treatment. While they are not considered competitors — transplant search coordinators will search all registries — each organization, and its online patient search engine, has a unique profile. The NMDP Registry includes nearly 7 million adult bone marrow donors and close to 70,000 cord blood units. MatchView’s searchable inventory covers the U.S. and some international centers, but NMDP transplant centers have access to all globally available donors and cord blood units as well.





Gift of Life is an associate donor registry of the NMDP with 125,000 bone marrow donors and 1,000 cord blood units. It contributes to a diverse worldwide pool of bone marrow donors and cord blood units by specifically focusing on the Jewish community. Donor drives are held at synagogues and Jewish community centers, but anyone who wishes to be tested or donate is included, regardless of background.

For searches aimed primarily at unrelated cord blood units, patients often turn to the NYBC's National Cord Blood Program, which has received cord blood donations from more than 45,000 mothers. The racial distribution of this inventory is approximately 40 percent Caucasian, 20 percent



Hispanic, 10 percent Asian, 10 percent African-American and 20 percent mixed ethnicities.

### Managing Patient Expectations

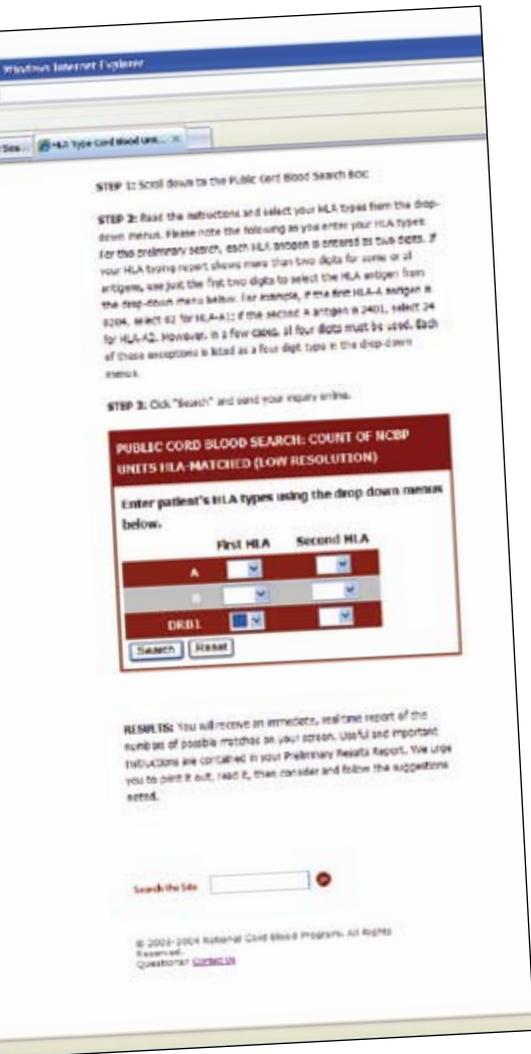
With search coordinators working on behalf of patients around the country, why should patients be able to perform informal searches on their own? According to Lyndsey Aspaas, BS, CHTC, senior search advocate at NMDP's Office of Patient Advocacy, one of the barriers some patients face after diagnosis is receiving a referral to a transplant physician to evaluate whether transplant is even an option.

"While the majority of physicians today are aware that transplants with unrelated bone marrow donors or cord blood donors are potential treatments, a considerable number of medical professionals do not know who to refer their patients to or still don't think it's even an effective treatment," she said. "A lot of education is still needed to get physicians to consider transplant consultation early on. Results showing a potential match or partial match may help patients broach the subject with their physicians."

Scaradavou agrees that the medical community as a whole still has limited knowledge of these procedures. "Cord blood transplantation is a relatively recent treatment option, and some doctors may not consider it right up front, so a patient who has done a search

online and has a sort of 'first view' of the searchable inventory can be a better participant in their own care," she said. "Patients look up medications, treatments ... they like to investigate and they usually come in with a lot of helpful information."

This patient-centered model of health care delivery gives individuals the resources they need to decide among their options, but also helps relieve some anxiety and stress that comes with a serious medical diagnosis. "We have found that this online application empowers patients to have some level of control over a situation that, from a medical standpoint,



## While patients now may be more educated or savvy than their predecessors, today's advancing technology is not without its limitations.

Working to combat the occasional misunderstandings about what these patient search tools are intended to do or capable of producing is another matter.

and practical," said NMDP's Murphy. "They want their information in real time and they don't want to go through a gate keeper, and MatchView is one of the ways to satisfy their expectations."

Other benefits to these online search tools are anonymity and ease of use. Patients do not need to provide personal identification, only their HLA typing data, information that is accessible in patient lab reports. For patients who may have trouble interpreting these reports, case managers, patient advocates and customer service representatives at NMDP, the National Cord Blood Program and the Gift of Life Bone Marrow Foundation are equipped to help.

"Our concern is whether or not these patients would understand what they're looking at. Most people 'get it,' but for those who don't, all they have to do is call us up and we'll explain it to them," Feinberg said. NMDP, likewise, stresses an important point on the MatchView Web site: "Patients are not responsible for finding their own donor," explained Murphy. "It's a message that we have always tried to deliver. This is just to give them a broad view of what may be out there for them."

### Patterns of Use

While patients and nonpatients alike can enter HLA typing data into the search tools and view immediate reports at any time — databases are updated continuously and may generate varying results depending on the day of the search — a difference of opinion exists on the best time for patients to use these resources. NMDP staff note that MatchView is not appropriate for patients who already are working with a transplant center. "Once they are working with a transplant center, they will get up-to-date information from coordinators and doctors regarding donor activity and potential matches," Aspaas said. "And transplant centers are able to see a worldwide summary under our collaborative relationships with those outside the U.S."

they don't have a lot of control over," Feinberg said. "These preliminary searches and the literature available on our Web site helps them be less overwhelmed and better educated on [cellular and biological therapeutic] options they may never have been familiar with before."

While not all patients are interested in this level of involvement, a growing group of patients dubbed "high info seekers" have come to expect these types of resources. "This group, regardless of what they've been told, is going to go out and do their own research, and they usually rely on the Internet since it's the most up-to-date

### Potential Difficulties

While patients now may be more educated or savvy than their predecessors, today's advancing technology is not without its limitations. "These tools only run on HLA data; it doesn't take into account any other information, and choosing a cord blood unit or a bone marrow donor is a medical decision," said NYBC's Scaradavou. "Sometimes the results give patients more hope than there is. They may see a potential matched cord blood unit, but it may not be large enough, it may not have enough cells, or there might be another parameter that doesn't make it available."



## SEARCH TOOLS FOR PATIENTS

### **National Marrow Donor Program**

Visit [www.marrow.org](http://www.marrow.org) under > Patients and Families > Transplant Process > Search Process.

### **NYBC's National Cord Blood Program**

Visit [www.nationalcordbloodprogram.com](http://www.nationalcordbloodprogram.com) under Public NCBP Cord Blood Search.

### **Gift of Life Bone Marrow Registry**

Visit [www.giftoflife.org](http://www.giftoflife.org) under Patients > Public Donor Search.

Gift of Life's Feinberg disagrees. "I think it's still a good idea for patients to use these tools even when they are working with transplant coordinators," he said. "When they are newly diagnosed and they want to feel assured that their health care providers are doing everything they can to access all sources of donors, these resources are very valuable."

Although these Web tools are still in their infancy, preliminary data shows significant traffic to these sites. Within its first year "live," MatchView received nearly 7,000 hits to its Web page, although NMDP cannot yet collect data on the number of actual MatchView searches performed. Up and running less than a year, Gift of Life has had more than 200 "PubSearch" requests thus far. User data are not available for the National Cord Blood Program's online search tool, but since its inception, the program has provided cord blood units for transplantation to more than 2,000 recipients — approximately

one-third of all cord blood transplants from unrelated donors worldwide.

### **Future Enhancements**

All three online search tools are offered along with answers to frequently asked questions about HLA

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matching, individual results, the search process itself and the "next steps" patients should take after completing their inquiry. Each host organization continues to make improvements and adjustments to its site to better facilitate patient-driven cellular and biological therapies. One of the "tweaks"

MatchView currently is undergoing is an expansion on the formats of data accepted. "There are 70 different formats of lab reports, and we want patients to be able to enter HLA typing however they've received it, whether it includes parentheses or a hyphen or backslash or an asterisk ... the system needs to be able to handle all of them," Aspaas said.

For Feinberg, who is 13 years post-transplant, any and all resources that empower patients with information to better determine what choices are right for them with respect to their own health care are a step in the right direction. "We have come a long way in the past 20 years," he said. "Patients used to know little as to what was happening in their search process, and now there's a tremendous effort to give them useful tools in readily consumable formats that provide a basis for discussion with their health care providers, and I think that's really exciting." ■