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## Preimplantation Genetic Diagnosis (PGD) on In-Vitro Fertilization (IVF) Websites: Presentations of Risks, Benefits and Other Information

Robert Klitzman, M.D.<sup>a</sup>, Beata Zolovska, M.D.<sup>b</sup>, William Folberth<sup>b</sup>, Mark V. Sauer, M.D.<sup>c</sup>, Wendy Chung, M.D. Ph.D.<sup>d</sup>, and Paul Appelbaum, M.D.<sup>e</sup>

<sup>a</sup> Associate Professor of Clinical Psychiatry, College of Physicians and Surgeons and Mailman School of Public Health, Columbia University, New York, NY

<sup>b</sup> Columbia University Medical Center, New York, NY

<sup>c</sup> Professor of Obstetrics and Gynecology, College of Physicians and Surgeons, Columbia University, New York, NY

<sup>d</sup> Assistant Professor of Pediatrics and Medicine, College of Physicians and Surgeons, Columbia University, New York, NY

<sup>e</sup> Dollard Professor of Psychiatry, Medicine, and Law, College of Physicians and Surgeons, Columbia University, New York, NY

### Abstract

**Objective**—To examine information on Preimplantation Genetic Diagnosis (PGD) presented on In-Vitro Fertilization (IVF) clinic websites.

**Design**—We systematically sampled every third IVF clinic on the 2004 CDC provider list.

**Setting**—The Internet.

**Patients**—None.

**Interventions**—None.

**Main Outcome Measures**—Benefits, risks and other types of information mentioned regarding PGD.

**Results**—Of 135 sites examined, 88.1% had websites, and 70% mentioned PGD, of which 27% were university/hospital-based and 63% were private clinics. Sites mentioning PGD listed uses/benefits of PGD far more than the risks involved. Of these sites, 76% described testing for single gene diseases, but fewer mentioned risks of missing target diagnoses (35%), or risks for loss of embryo (18%); and 14% described PGD as new or controversial. Private clinics were more likely than other programs to: be on either the East or West Coasts; list certain PGD risks (e.g., diagnostic error); note that PGD was new or controversial; reference source of PGD information; provide accuracy rates of genetic testing of embryos; and offer gender selection for social reasons.

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Corresponding Author: Robert Klitzman, M.D. HIV Center, Unit 15, 1051 Riverside Drive, New York, NY 10032, Phone: (212) 543-3710, Fax: (212) 543-6003, rlk2@columbia.edu.

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**Conclusions**—Most IVF clinics advertise PGD on-line, but the scope and quality of information about it varies widely, emphasizing benefits while minimizing risks. Clinics and patients may benefit from more thorough and consistent presentation of PGD, drawing on available evidence to best provide a realistic portrayal of PGD.

### Keywords

PGD; IVF; ART; internet; infertility; advertising; risk; benefit

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### Introduction

The integration of PGD into the field of assisted reproduction has progressed rapidly, and the public's knowledge of its use has been promoted through the popular media and internet. However, the accuracy and completeness of the portrayal of PGD on websites has not been examined, and remains unregulated. In the past decade, PGD has become more widespread and accessible, yet remains a relatively new concept to most patients. The number of genetic disorders that can be assessed through PGD is ever-increasing (1); however, few data are available on patterns of its contemporary use in the United States. PGD has engendered controversy since it was developed, including recent debates about the utility of preimplantation genetic screening for aneuploidy to increase the success of IVF for older women (2,3) and ongoing concerns regarding potential individual and social risks inherent in its widespread application (4).

In general, many potential patients use the internet to obtain information on both diseases and providers. Unfortunately, health care information presented on the internet in a variety of medical specialties is frequently incomplete and inaccurate (5). As a result, as outlined on Table 1, the AMA has issued guidelines with respect to health information websites (6).

Yet, websites in several areas of medicine have been found not to follow these voluntary guidelines consistently. For example, recently, we found that websites recruiting participants for studies in diabetes and depression often presented apparently unbalanced information, with most sites mentioning incentives, but not risks (7). Similarly, researchers in a study of websites on breast augmentation found that they would recommend only 15% of the sites to their patients (8), and the quality of information has been found to vary widely on websites for osteoporosis, diabetes and oncology (9).

Huang et al. (2004) examined IVF clinic websites, and found that most did not follow AMA guidelines, with differences emerging between university/hospital-affiliated vs. non-hospital clinics (10). Specifically, most did not identify the source of content, provide affiliations and relevant financial disclosures for authors, provide information about patient privacy, or have a search function or a site map, though on each of these indices, hospital-based clinics were more likely than non-hospital based clinics to do so. Yet several of these AMA guidelines may not be as relevant for IVF clinic websites as for other types of health information websites (11), such as those that also directly sell products on-line, or collect information from site visitors; and the quality of IVF clinic websites may best be assessed using other criteria. Nevertheless, Niederberger (12) argued that IVF clinics should still improve their websites, to avoid potential external regulation of these sites.

The Society for Assisted Reproductive Technologies (SART) and American Society for Reproductive Medicine (ASRM) issued guidelines for advertising in 1999, revising them in 2004 (13), and deemed that adherence to these guidelines was mandatory for SART membership. Yet, in 2005, many clinics were found not to be following these directives (14). Among hospital-based and private clinics, respectively, 39.7 and 55.5% listed IVF success

rates ( $p < .025$ ), but only 19.2 and 23.2 % listed live birth rates, and only 10.3 and 17.1% listed success rates based on indication for IVF. PGD was listed as being available at 30.9% and 39.3% of these clinics.

Since then, in response to these prior reports and/or growing internet use, clinics may have altered the content and nature of their websites. At the same time, IVF practices have been changing, with increased clinical experience and improvement of techniques. Still, what information clinics provide about PGD, how often it is presented, and how the information is offered, have not been examined. Internet advertising may shape whether prospective patients decide to seek PGD, what indications they seek PGD for, and where they undergo the procedure. Data on information provided about PGD on websites is important, too, since increasingly, many patients rely on the internet as a major and/or first source of health information (15-16). Such websites provide important information to prospective patients since both patients and physicians in general are often deficient in their knowledge of genetics (17-19). Hence, it is important that IVF clinic websites provide clear, accurate, and balanced information. PGD decisions are extremely complex and require additional discussion with health care providers. Patients can not be fully informed via websites alone. However, data demonstrate increasing numbers of patients are in fact making critical health care decisions based on information that they obtain on the internet (20-21). Specifically, the internet can strongly shape whether, where, when, and how prospective patients decide to seek treatment for particular problems (20-21). No doubt, many patients come to an IVF clinic already leaning toward having PGD performed, and then discuss this possibility further with a clinician. However, prior even to arriving in a clinician's office, many potential patients may well search the web for information. Some potential patients may decide not to go to an IVF clinic and/or seek PGD because of what they read. Hence, though practitioners may not view their websites as major sources of information for prospective patients, these potential patients – the numbers of whom remain wholly unknown – may nevertheless be affected in their decisions and views by information gleaned from these sites. In sum, many critical questions persist about how IVF websites present PGD, particularly its risks and benefits. We believe that such data could help providers improve their presentation of information to the public on the internet.

## Methods

We reviewed United States IVF clinics listed in the 2004 Assisted Reproductive Technology (ART) annual success rates report, published by the Center for Disease Control and Prevention (CDC) (22), as mandated by the 1992 Fertility Clinic Success Rate and Certification Act. The 2004 report lists 411 U.S. fertility clinics, providing information on the type, number and outcome of ART cycles (22). We systematically reviewed every 3<sup>rd</sup> clinic listed alphabetically by state, for a total of 135 sites. Of these clinics, 16 did not have an active website, and hence were not examined. For consistency, we downloaded and printed every page from each clinic's website between February 15 - February 25, 2007. If the website included a link that redirected the user to another URL of an unrelated site, the information obtained from the new URL was not included in these data.

Dr. Klitzman and two Research Assistants (RAs) each independently read a randomly selected sample of websites, to familiarize themselves with the entire content. Working closely with Dr. Klitzman, the RAs then reread each website, systematically developing categories to code. Such categories included, e.g., whether sites included information about benefits and risks of PGD information provided (see below). This coding team then worked together to reconcile the independently developed coding schemes into a single scheme, and together developed a coding manual, defining each code, and a common set of criteria for use by coders in identifying instances of each phenomenon. The investigators developed a draft of this framework only

after reviewing a subset of websites, in order to allow initial framework development to occur in the context of the data.

Working independently, the two RAs then reviewed websites and assigned codes. The RAs and Dr. Klitzman identified codes that were unclear or were coded differently, to develop consensus on the coding. Discrepancies were resolved by a discussion among the coders, and the manual was refined to accommodate necessary changes. The two RAs then each independently coded 10 randomly selected websites, and achieved 100% consensus. They thus coded the remaining sites, using the coding manual.

In the end, 7 broad categories and 40 subcategories were all coded, as listed below:

- Background Information: Geographic location (East Coast, Midwest, Northeast, South, West). We also noted volume (i.e. <100, 100-200, and > 200 IVF procedures with fresh non donor eggs per annum) as obtained from the CDC website. (i.e., rather than from the sites themselves).
- Type of Clinic: university/hospital-based vs. stand-alone/private (which we readily determined through the institutional affiliation or description of the clinic provided on each website).
- General Information: Mention of: explanation of IVF, explanation of PGD, IVF as required for PGD, amniocentesis or chorionic villus sampling to confirm results of PGD or as an alternative for genetic screening, references for source or attribution of PGD information, any ethical issues.
- Risks of PGD: Mention of: risk for false positive and false negative diagnosis, risk for loss of embryo due to PGD, technique described as “new” or “controversial,” cost, and other risks. PGD still remains relatively new. Though many uses are well established, others such as testing for single mutations found to be associated to varying degrees with particular disorders, e.g., Alzheimer's or *BRCA1/BRCA2* are newer, and may be less established. Institutions may not require IRB approval for use of PGD, but some practitioners may see particular uses (e.g., *BRCA1/2*) as new, or controversial in the sense that questions remain concerning the practice (e.g., the indications for, utility of, or necessary counseling for, testing for such markers).
- Benefits/Uses of PGD: Mention of: testing for single gene disorders to avoid their transmission (i.e. specific diseases involving single genes), testing for aneuploidy/chromosomal abnormalities, gender selection to avoid X-linked disease, gender selection for other (i.e. social) reasons, history of multiple miscarriages, advanced maternal age, repeated IVF failure, family history of genetic disease, decreasing chance of multiple births, having a child with a genetic or chromosomal disease, other benefits/uses of PGD, anyone having IVF, and anyone in general, and names of specific genetic or chromosomal disorders.
- Format: Whether, how, and to what degree websites present clear, accurate and balanced information about PGD, reflected in both the content and the form of presentations of information. Clinics appeared to emphasize PGD to varying degrees. To capture a sense of these differences, we coded whether: PGD is mentioned on main page of website vs. only on other pages that required multiple clicks to reach, PGD information is linked from main IVF website, and a photo or visual representation of a healthy baby appears on the page with PGD information.
- Other: Date for information provided (i.e., of copyright), other options for avoiding transmission of genetic defects discussed, contains information to make appointment

with genetic counselor, rate of accuracy of genetic testing of embryo, posting of consent forms for IVF, and/or PGD, and disclosure of funding or competing interests.

Of note, no websites listed specific costs of PGD. Almost none reported the extent of doctors' own experience with PGD (i.e., the volume of PGD they have performed). A few mentioned that the first or second baby had been born at their clinic through PGD, but did not give numbers of PGD procedures done. Hence, we did not code for these characteristics.

We did not obtain Institutional Review Board (IRB) approval, since we did not collect data concerning any human subjects, and assessed only publicly-available websites. We had no conflicts of interest.

## Results

Overall, of 119 IVF sites systematically surveyed, 83 (70%) mentioned that the clinic conducted PGD. As depicted in Table 2, websites mentioning PGD were more likely to be performing a high volume of in-vitro fertilization ( $p < .003$ ), and to be free-standing, independent private clinics (vs. affiliated with major hospitals or universities) ( $p < .045$ ), and there was a trend for them to be located in certain regions (e.g., less common in the Midwest) ( $p < .067$ ).

Sites that mentioned PGD typically mentioned its benefits and applications far more often than its risks and liabilities. For example, 76% referenced testing for single gene disorders, while only 35% acknowledged risks for errors in target diagnosis, with only 18% mentioning the risk for loss of embryos due to PGD, and only 14% of sites characterized PGD as new or controversial.

Among the sampled sites that mentioned PGD, 22 (27%) were located at major hospitals and/or universities, while 61 (63%) were at private stand alone clinics not affiliated with a university or hospital. Private stand-alone clinics differed from hospital-based clinics in geographic region, with stand-alone clinics being more likely to be on the East Coast and in the West, and less likely to be in the South or Northeast ( $p < 0.036$ ). Private clinics were more likely to list: certain risks of PGD (e.g., errors in diagnosis) ( $p < 0.034$ ); PGD being new or controversial ( $p < 0.018$ ); references for source of PGD information ( $p < 0.012$ ); rate of accuracy of genetic testing of embryo ( $p < 0.053$ ); and offering gender selection without a genetic reason (e.g., for social purposes) ( $p < 0.026$ ).

## Discussion

These data suggest wide variations in the provision of information about PGD by IVF clinics on the internet. Private clinics (i.e., not affiliated with universities or hospitals) provided more comprehensive information, including risks and shortcomings of the procedure, but also provided a more extensive list of indications that was more likely to include gender selection for social reasons (i.e. "family balancing"), which has been controversial.

These data should be of interest to IVF clinics and PGD providers, providers who may refer patients for IVF/PGD, and others involved in healthcare (e.g., geneticists, genetic counselors, obstetricians and pediatricians). IVF clinics can use this information to compare their websites to those of other clinics, in hopes of optimizing and enhancing the information they provide to patient-consumers. Providers should be encouraged to add certain types of referenced information (e.g., source and year of publication of information about PGD), lists of other publications for sources of information regarding PGD, and known risks, costs, benefits of PGD, and number of cases performed. More comprehensive discussions of PGD will provide prospective patients with realistic expectations, and ultimately decrease anxiety and frustration

often associated with IVF and PGD. Of note, listing of references for information provided and disclosure of competing interests, which the AMA included in its guidelines, and which were found in prior research usually to be lacking on IVF websites (10), were also rarely provided on these websites. One could argue that some of the features examined here are not important, and need not be included. But some potential patients may be interested in such information, and use it to make better informed decisions.

Currently, ASRM guidelines do not exist concerning presentation of PGD on websites. Yet in light of the wide variability in the quantity and quality of information provided by different clinics, one could argue that more complete and thorough information could help patients. Moreover, greater uniformity among clinics in the amount of information provided could be of particular assistance to patients who may now be confused by varying and disparate information on different websites. Such enhancements of websites could potentially be accomplished by clinics on their own, without involvement of professional organizations or others. The data here can help guide many IVF clinics in enhancing their current websites, by including types of information that some other sites now provide, and that can help prospective patients. Moreover, there may be advantages to having uniform guidelines or even a single website not affiliated with any particular clinic, perhaps sponsored by a professional organization like ASRM, with accurate information about PGD to which individual clinics could link.

The development of guidelines for PGD use has been controversial (11), as is the question of whether and how non-compliance with the guidelines would be handled. Voluntary guidelines for websites, however, may help to establish an informational baseline to which IVF clinics can compare the information on their sites. Market forces themselves may lead clinics to greater conformance with these guidelines over time. At present, PGD information on websites can clearly be improved.

This study has several limitations. We did not examine every website, but sampled every third one. However, we have no reason to believe that these sites are not representative of the entire set. We did not systematically compare IVF websites with those addressing other medical conditions or procedures and hence are unable to draw conclusions as to whether IVF sites are more or less problematic. However, as mentioned above, websites in several other areas of healthcare have also been found often not to meet fully AMA and other relevant guidelines. We coded for a finite number of characteristics, as indicated, but did not code for others. For instance, several sites mentioned that they sent embryos to an outside lab for testing, but these sites rarely, if ever, named the lab. Such additional characteristics can be explored in further research.

The deficits in the information about PGD on IVF clinic websites are not a unique phenomenon, but rather one manifestation of a larger problem of integration of commercial interests with presentations of supposedly objective medical information on the internet. The use of the internet as a major source of health information for patients remains relatively new and is rapidly evolving. The potential dangers of presentation of biased information on complex and costly medical procedures need to be heeded, explored and addressed. There are clear opportunities for improvement of practices on internet advertising. Future studies are needed to assess further patterns of use of the internet in medical decisions and health seeking behavior. Surely, patient and provider use of the web will continue to grow as more patients obtain regular internet access. In sum, to ensure that information provided is as useful and appropriate as possible constitutes a vital goal.

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**Table I**  
**Areas of AMA guidelines for information on health websites\***

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Principles of Content

- Definition of Content: e.g., includes all material, listings, indexes, etc.
- Site Ownership: e.g., website and copyright ownership should be indicated, including affiliations.
- Site Viewing: e.g., optimal information about platforms and browsers should be provided.
- Viewer access, payment and privacy: e.g., should be provided and easy to find.
- Funding and Sponsorship: e.g., advertising should be clearly distinguished from content.
- Quality of editorial content: e.g., content should be reviewed for quality. Clinical content should be reviewed by experts not involved in creation of the content. Affiliations for authors and content producers should be clearly indicated.
- Linking: e.g., intrasite content links and external links should be maintained and monitored.
- Intersite Navigation: e.g., sites should not prevent viewers from returning to a previous site or redirect the viewer to a site the viewer did not intend to visit.
- Navigation of Content: e.g., the site should include a site map, a help function or frequently-asked-questions page, customer service information, and a search engine.

Principles for Advertising and Sponsorship

- Digital advertisements must be readily distinguishable from editorial content.
- All financial or material support will be acknowledged.

Principles for Privacy and Confidentiality

- Privacy: e.g., a link to the privacy policy of the Web site should be provided and easily accessible.
- Confidentiality: e.g., patients should be aware when they provide information about their individual medical conditions in the context of such discussions that information may be linked with a personal identifier. Patients have a right to privacy that should not be infringed without express informed consent.

Principles for E-Commerce

- Intended to ensure that users and purchasers of information, products, and services on the site will have access to secure, efficient transactions for online and remote customer fulfillment.
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\* Taken from [<http://www.ama-assn.org/ama/pub/category/1905.html>]

**Table 2**  
**Characteristics of IVF clinics and information about PGD on Clinic Websites**

	All IVF Clinics			IVF Clinics Mentioning PGD			P-values**		
	N = 119	All Clinics N = 83	P-values*	IVF Clinics Mentioning PGD		P-values**			
				Hospital/University-Based Clinics N = 22	Private Clinics N = 61				
<b>CHARACTERISTICS OF CLINIC</b>									
<b>Region</b>									
East Coast	17	14%	15	18%	1	4.5%	14	23.0%	0.036
Midwest	33	28%	17	20%	4	18.2%	13	21.3%	
Northeast	21	18%	16	19%	8	36.4%	8	13.1%	
South	27	23%	19	23%	7	31.8%	12	19.7%	
West	21	18%	16	19%	2	9.1%	14	23.0%	
<b>Type of Clinic</b>									
Major Hospital	38	32%	22	27%	22	100.0%	0	0.0%	
Standalone	81	68%	61	73%	0	0.0%	61	100.0%	NS
<b>Volume</b>									
<100	40	34%	20	24%	4	18.2%	16	26.2%	
101-200	34	29%	26	31%	8	36.4%	18	29.5%	
>201	45	38%	37	45%	10	45.5%	27	44.3%	
<b>INFORMATION ABOUT PGD PROVIDED</b>									
<b>General Information</b>									
Explanation of IVF	71	60%	71	86%	18	81.8%	53	86.9%	NS
Explanation of PGD	63	53%	63	76%	16	72.7%	47	77.0%	NS
Website mentions that IVF is required for PGD?	61	51%	61	73%	17	77.3%	44	72.1%	NS
Need for amnio/chorio with PGD	16	13%	16	19%	3	13.6%	13	21.3%	NS
References for source or attribution of PGD information	12	10%	12	14%	0	0.0%	13	21.3%	0.012
Ethical discussion	10	8%	10	12%	1	4.5%	9	14.8%	NS
<b>Risks of PGD</b>									
Risks for missing target diagnosis	29	24%	29	35%	4	18.2%	26	42.6%	0.034
Risks for loss of embryo due to PGD	15	13%	15	18%	3	13.6%	13	21.3%	NS
Technique is experimental, new or controversial	12	10%	12	14%	0	0.0%	12	19.7%	0.018

	All IVF Clinics			IVF Clinics Mentioning PGD		
	N = 119			N = 61		
	All Clinics N = 83	Hospital/University-Based Clinics N = 22	Private Clinics N = 61			
Cost mentioned	11 9%	2 9.1%	9 14.8%	NS		
Other risks	9 8%	1 4.5%	8 13.1%	NS		
<b>Benefits/Uses of PGD</b>						
PGD testing for single gene diseases	63 53%	16 72.7%	48 78.7%	NS		
PGD testing for aneuploidy/chromosomal abnormalities	59 50%	16 72.7%	44 72.1%	NS		
Gender selection to avoid x-linked disease	22 18%	3 13.6%	20 32.8%	0.071		
Gender selection without genetic reason (i.e. social gender selection)	11 9%	0 0.0%	11 18.0%	0.026		
For those with family history of genetic disease	58 49%	14 63.6%	45 73.8%	NS		
For those with h/o multiple miscarriages	40 34%	9 40.9%	32 52.5%	NS		
For advanced maternal age	38 32%	9 40.9%	30 49.2%	NS		
For repeated IVF failure	29 24%	7 31.8%	23 37.7%	NS		
PGD as beneficial for avoiding problems of multiple births	6 5%	1 4.5%	5 8.2%	NS		
For those with an affected child	11 9%	2 9.1%	9 14.8%	NS		
Other benefits of PGD	14 12%	1 4.5%	13 21.3%	0.063		
PGD testing for specific disorders - # disorders listed	51 43%	13 59.1%	39 63.9%	NS		
Anyone having IVF	2 2%	0 0.0%	2 3.3%	NS		
Anyone in general	1 1%	0 0.0%	1 1.6%	NS		
<b>Format</b>						
PGD mentioned on main page of website	16 13%	6 27.3%	10 16.4%	NS		
Link from main website	29 24%	4 18.2%	25 41.0%	0.045		
Picture of a baby by PGD info (anywhere on page)	33 28%	7 31.8%	26 42.6%	NS		
<b>Other</b>						
List any date for information provided (i.e. Copyright)	77 65%	5 22.7%	18 29.5%	NS		
Other options for avoiding genetic defects discussed	18 15%	3 13.6%	15 24.6%	NS		
Prompt to call to make appointment with genetic counselor	15 13%	3 13.0%	12 19.7%	NS		
Rate of accuracy of genetic testing of embryo	9 8%	0 0.0%	9 14.8%	0.053		
Consent forms provided for IVF	6 5%	2 9.1%	3 4.9%	NS		
Consent form provided for PGD	3 3%	2 9.1%	1 1.6%	NS		
Disclosure of funding and competing interests	1 1%	0 0.0%	1 1.6%	NS		

\* Comparisons of all IVF clinics to those that mention PGD.

\*\* Comparison of hospital/university-based vs. private clinics.