First Invitational International Forum on

Cross-Border Reproductive Care: Quality & Safety

PATIENT & PHYSICIAN PROMPTERS

Introduction

The companion Patient and Physician Prompters were prepared for, and refined at, the First Invitational International Forum on Cross-Border Reproductive Care. This Forum took place from January 14 to 16, 2009, in Ottawa, Canada.

The event was planned by a steering committee of international experts and attended by more than 50 delegates from academic institutions, government bodies, and patient and professional organizations from over a dozen countries. There were also participants from several multinational organizations, including the World Health

Organization and the European Commission.

The goal of the Forum was to share experiences and build agreement among participating countries and organizations on the principles underpinning **safe**, **quality care** when cross-border reproductive care (CBRC) occurs: that is, when patients seek and obtain reproductive care outside the country in which they reside.

The Patient and Physician Prompters reflect two of the Forum's objectives, namely to: (1) develop agreement on the information required for health professionals before, during, and after treatment of individuals undergoing CBRC; and (2) develop agreement on the information required to support patients who choose to access care and assist them in making informed choices about CBRC.

Initial drafts of the Patient and Physician Prompters were developed by Dr. Eric Blyth (University of

Huddersfield, UK) and Dr. Ed Hughes (McMaster University, Canada), respectively, in light of international patient and physician surveys they conducted. Participants at the Forum believed the prompters would be useful tools to promote safe, quality care, and proposed a number of revisions to the initial drafts with this goal in mind.

This document is the final product of this process. Individuals and organizations are encouraged to disseminate, make use of, and customize the prompters according to their needs.

A series of questions to help users judge the validity of information found on web sites is attached as the appendix *Getting Good Information from the Internet*.

Prompters are detailed reminder tools that can be customized to fit a range of situations. They are useful in organizing discussions and supporting information exchange and proactive decisionmaking in conversations between patients and physicians.

PATIENT PROMPTER

Introduction

This prompter is designed to help patients who have decided to undertake crossborder reproductive care to prepare, by providing a framework for considering safety and quality of care issues.

Using multiple sources of information may help you get a more complete picture of your destination clinic - what sources have you used so far, to obtain and verify information concerning costs, success rates, care packages, waiting times, availability of donor sperm/eggs/embryos? Some sources of information you may wish to explore include clinics, physicians, other patients, patient organizations in your own country, and national government agencies in your own and in the destination country.

Questions about your destination clinic

- 1. What are the qualifications and experience of the clinic's medical, nursing and scientific staff?
- 2. What clinical and laboratory accreditation/certification and/or professional standards does the clinic comply with?
- 3. Does the clinic have a complaints/incident-reporting procedure?
- 4. Are patient records maintained securely and how long will they be kept?
- 5. Does the clinic provide information in a language you understand or provide access to a competent interpreter?

Information about your proposed treatment

- 1. Have the safety and effectiveness of the treatment you seek been established?
- 2. What are the risks to you or any children you may conceive, particularly if a multiple pregnancy occurs?
- 3. What treatment is provided in the care package? Is information provided on what you should do if you need emergency care and treatment while abroad, and are unable to access the out-of country clinic?
- 4. If you need part of your treatment (e.g. cycle monitoring such as blood tests, or

ultrasound scans) in your own country, how will this be provided?

Provision of counselling and emotional support

- 1. Is professional counselling available at all stages of treatment in a language that is understandable to you?
- 2. Do you have support from friends or family or from other sources for the treatment you propose?

If your proposed treatment involves surrogacy or a donor procedure

NB It is strongly recommended that you seek legal advice on issues such as: the citizenship of any child born through a procedure involving surrogacy; how parentage is determined in the country of birth for any child born through a procedure involving surrogacy; and whether a surrogate or donor would have parental or other rights/responsibilities with respect to the child.

- 1. What assurances are given that gametes or embryos actually come from the chosen donor?
- 2. What medical and psychological screening of the donor/surrogate is undertaken?
- 3. What assurances are given that the donor/surrogate has given his or her informed consent?
- 4. What assurances are given that the surrogate is healthy and free of communicable disease prior to treatment?
- 5. What assurances are given that the surrogate will avoid high-risk activity during pregnancy?
- 6. What assurances are given that the surrogate will have safe, effective obstetric care?
- 7. What information is available to you about the donor/surrogate? Can this be updated and given to you in the future and can you request further information from the donor for medical/genetic issues?
- 8. What expenses/financial incentive/other benefits if any have been paid to the donor/surrogate, and how does the clinic verify this?
- 9. How does the clinic protect confidentiality of information between donor/

surrogate and you?

- 10. Can you use the same donor to have another child in the future?
- 11. Is there a limit on the number of children conceived from a single donor?
- 12. If gametes or embryos are to be imported to your home country, what arrangements need to be made?
- 13. Does the donor/surrogate have any legal or financial responsibility for offspring?
- 14. Does the donor/surrogate have any right to information about the outcome of his/her donation?

Issues for offspring born as the result of surrogacy or a donor procedure

- 1. Will any information about the donor/surrogate be available to your child? If so, at what age and how will they receive or apply for this information?
- 2. Where will the information be held and for how long?
- 3. What will you tell your child about how he/she was conceived? How will you do this and where will you get support and information about telling?
- 4. If information about the donor/surrogate is not available to your child, how will you explain this to him or her?
- 5. Are there any legal implications for children conceived by donor gametes/surrogacy either in the specific destination country or your own country?

Patients may also wish to review the physician prompter, and take it with them to appointments with health professionals.

PHYSICIAN PROMPTER

Introduction

This prompter is designed to help physicians effectively counsel and prepare patients who choose to leave their country for care, in order to minimize the risks around quality and safety of cross-border fertility treatment. It also provides some suggestions for communication and information transfer between themselves and physicians in destination countries. While not all questions may be applicable to your patient, this prompter provides a framework to ensure relevant issues are discussed and addressed prior to patients arranging travel and paying for cross-border fertility care.

Checklist for Clinic-to-Clinic Communication

From the home to the out-of-country clinic:

- 1. Consultation letters summarizing patient clinical and other relevant issues
- 2. History and physical documentation
- 3. Pertinent lab and imaging reports, including infectious disease screening results
- 4. List of risk factors for pregnancy, including uterine anomalies and previous adverse pregnancy outcomes
- 5. Previous treatment records
- 6. Ovulation induction track sheets, with doses and responses
- 7. IVF records with details of oocyte, embryo and sperm number and quality where appropriate

From the out-of-country to the home clinic:

Patients should be encouraged to obtain from the treating clinic, the following information:

- 1. Details of evaluation
 - a. Of patient, including genetic screening.
 - b. Of gamete/embryo donor if appropriate

- 2. Details of treatment
 - a. Choice of and response to medication
 - b. Number and quality of oocytes and embryos
 - c. IVF, ICSI, PGD?
 - d. Number of embryos transferred and number cryopreserved
- 3. Plans for further care
 - a. Pregnancy confirmation
 - b. Luteal phase support
 - c. Genetic screening if appropriate
 - d. Request to home clinic to ensure referral to obstetrical care provider

Medical Issues

- 1. Have alternatives to treatment in the home country been explored with the patient?
- 2. Are there any pre-treatment tests or treatments that could be done before departure that would enhance the success of care?
- 3. Is the treatment being sought medically appropriate for this patient?
- 4. Is there a reasonable prognosis for treatment success?
- 5. Does the patient know about the policies and practices of the out-of-country clinic with respect to the number of embryos transferred? Is the patient aware of the risks associated with multiple pregnancies?
- 6. Are the caregivers adequately trained and certified?
- 7. Is the facility accredited and if so, by whom?
- 8. When donor gametes are being sought:
 - a. What assurances are present that gametes actually come from the chosen donor?
 - b. Are the donors and semen adequately screened and tested for infectious or genetic disease?
- 9. When surrogacy or gestational carrier are sought, what assurances are present that the carrier:
 - a. is healthy and adequately screened and tested for infectious or genetic disease prior to treatment?
 - b. will avoid high-risk activity during pregnancy?
 - c. will have safe, effective obstetric care?

- 10. What information will be provided to the home clinic?
 - a. Type of treatment received
 - b. Details of IVF response, including number and quality of embryos transferred?
 - c. Complications, unexpected events, evidence of OHSS
- 11. What follow-up will be provided by the out-of-country clinic?
 - a. Will pregnancy confirmation be done by the home clinic?
 - b. Will counselling be available on treatment outcome and will future options be provided?

Emotional and Value Issues

- 1. Have patients been offered adequate counselling before departure, especially when multiple embryos are to be transferred, or gamete donation or surrogacy are being considered?
- 2. Will information and counselling in the destination country be adequate and provided in a language that is understandable to the patient?
- 3. Do the patients have support from their families and friends in this venture?

Clinicians may also wish to refer to the patient prompter.

FINDING ACCURATE INFORMATION ON THE INTERNET

With an unprecedented volume of health information on the web, how do you know the information you are reading online is accurate, trustworthy, and appropriate for your use? You can take steps to protect yourself from misleading health information by asking the following questions and carefully reviewing the website where you are collecting your information.

- What organization or individual is responsible for the operation and content of the website? Is the author or editor a medical or health professional with credentials? Does the website represent a reputable or credible medical institution, a government health department or agency, or a not-for-profit health organization? Web sites operated by pharmaceutical companies or commercial enterprises should be avoided.
- For whom is the site intended? Is it intended for the general public, or health care professionals, or students? Is there a privacy/confidentiality policy clearly stated regarding personal and non-personal information, medical information and email addresses?
- What is the purpose of the site? Does the site have a mission statement? Is it for information or educational purposes, or does it promote a particular product or service? Is there a declaration that the information provided on the site is meant to complement and not replace any information or advice from a health care professional?
- Is there advertising on the site which affects the information provided on the site? Be cautious of sponsors who sell prescription and non-prescription drugs, alternative or herbal remedies. Are all adverts clearly identified as advertising? Who is the website sponsor? Is it a health institution or company selling a product?
- Is the information or claims related to the benefits, treatments, products or services supported by clear references to scientific research results or published articles? Are the study author's qualifications listed? Be cautious of sites with claims using words such as "miracle", "secret ingredient" or "breakthrough". Does the information on the site or chat room promote the author's own interests or a commercial product?
- When was the information last reviewed or updated? Is the health information current? Are you able to easily contact the website through a valid email address or contact form?
- Does the website have a seal of approval as a website that has agreed to abide by

a code of conduct which confirms the reliability and credibility of the information posted?

These questions were developed in light of information found on the Health on the Net Foundation's website at www.hon.ch/