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A **STUDY GUIDE** BY CHERYL JAKAB



AUSTRALIAN TEACHERS OF MEDIA

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Filmmaker Shalom Almond wants a baby free from her family's history of blindness, but while modern medicine might offer that possibility, there's no manual for the moral minefield that comes with it.



Running time: 27 mins

Introduction

Love-Heart Baby (Shalom Almond, 2012) is a documentary film that explores up-to-date information on an important personal and ethical issue of our day: genetic screening. Technology is now available for people like Shalom Almond who want to make sure their unborn child is healthy, or 'has the best start possible'.

The film's strength is in being presented as a biographical narrative. It draws the audience into the thoughts and lives of the individuals making use of today's genetic technology. The audience gets involved in all the minute details of the decision-making processes in this very personal story, showing, as Almond says, that 'the process is so stressful, expensive and morally confusing it's taking over my whole life'.

The program at a glance

Filmmaker Shalom Almond and her husband Osker want a baby, but because Shalom has inherited an eye disease from her mother that leads to blindness, they don't want to enter a random genetic lottery. Now modern science has thrown them a bone. It's a controversial process called Preimplantation Genetic Diagnosis and it might just make them a baby with perfect eyes. So Shalom and Osker embark on the painful, expensive and morally fraught course that is embryo screening. It's a harrowing ride for them and their extended family, and the destination seems forever distant – until they take one last, risky turn that ultimately changes their lives.

Credits

Shalom Almond – Writer/Director/Co-Producer
 Katrina Lucas – Producer
 Lauren Drewery – Executive Producer/Story Editor

Overview of background science

- Patterns of inheritance, genotypes and phenotypes
- Genetic information & heritable disorders
- IVF, PGD & embryo selection

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Filmmaker Shalom Almond with her husband Osker

CURRICULUM AND EDUCATION SUITABILITY

Level: Year 10

LEARNING AREAS

- 1 Science Understandings:** Biological sciences
- 2 English:** Language; Literature; Literacy
- 3 Arts:** Media Arts
- 4 General capabilities:** Ethics; Critical and creative thinking

Reference: ACARA

<<http://www.australiancurriculum.edu.au/Curriculum/F-10>>

1. SCIENCE UNDERSTANDING

Biological sciences

The transmission of heritable characteristics from one generation to the next involves DNA and genes. (ACSSU184)

- Describing the role of DNA as the blueprint for controlling the characteristics of organisms
- Using models and diagrams to represent the relationship between DNA, genes and chromosomes
- Recognising that genetic information passed on to offspring is from both parents by meiosis and fertilisation
- Representing patterns of inheritance of a simple dominant/recessive characteristic through generations of a family
- Predicting simple ratios of offspring genotypes and phenotypes in crosses involving dominant/recessive gene pairs or in genes that are sex-linked
- Describing mutations as changes in DNA or chromosomes and outlining the factors that contribute to causing mutations

Science as a Human Endeavour

Use and influence of science:

Advances in science and emerging sciences and technologies can significantly affect people's lives. (ACSHE195)

- Investigating the applications of gene technologies

The values and needs of contemporary society can influence the focus of scientific research. (ACSHE230)

- Considering the use of genetic testing for decisions such as genetic

counselling, embryo selection, identification of carriers of genetic mutations and the use of this information for personal use or by organisation such as insurance companies or medical facilities

Science inquiry skills

Evaluating: Critically analyse the validity of information in secondary sources and evaluate the approaches used to solve problems. (AC SIS206)

- Describing how scientific arguments, as well as ethical, economic and social arguments, are used to make decisions regarding personal and community issues

2. ENGLISH

Language

Text structure and organisation:

Understand how paragraphs and images can be arranged for different purposes, audiences, perspectives and stylistic effects. (ACELA1567)

Literature

Responding to literature: Analyse and explain how text structures, language features and visual features of texts and the context in which texts are experienced may influence audience response. (ACELT1641)

Evaluate the social, moral and ethical positions represented in texts. (ACELT1812)

Literacy

Interacting with others: Use organisation patterns, voice and language conventions to present a point of view on a subject, speaking clearly, coherently and with effect, using logic, imagery and rhetorical devices to engage audiences. (ACELY1813)

Creating texts:

1. Create sustained texts, including texts that combine specific digital or media content, for imaginative, informative, or persuasive purposes that reflect upon challenging and complex issues. (ACELY1756)

2. Review, edit and refine students' own and others' texts for control of content, organisation, sentence structure, vocabulary, and/or visual features to achieve particular purposes and effects. (ACELY1757)

3. Use a range of software, including word processing programs, confidently, flexibly and imaginatively to create, edit and publish texts, considering the identified purpose and the characteristics of the user. (ACELY1776)

From <<http://www.australiancurriculum.edu.au/English/Curriculum/F-10#level=10>>

4. GENERAL CAPABILITIES

Critical and creative thinking

Inquiring – identifying, exploring and clarifying information: explore the coherence and logic of multiple perspectives on an issue

Reflecting on thinking, actions and processes: give reasons to support their own thinking, show awareness of opposing viewpoints and possible weaknesses in their own positions

Drawing conclusions and designing a course of action: identify a problem, isolate its important aspects, and use logical and abstract thinking to formulate a response

From <<http://www.australiancurriculum.edu.au/GeneralCapabilities/Critical-and-creative-thinking/Continuum>>

Ethical behaviour

Understanding ethical concepts and issues: identify ethical obligations and justify the need for these to be enacted

Reflecting on personal ethics in experiences and decision making: engage in reasoned debate to probe ethical concepts in issues of personal, social and global importance

Exploring values, rights and ethical principles: analyse the interplay between ethical and other considerations in making decisions

From <<http://www.australiancurriculum.edu.au/GeneralCapabilities/Ethical-behaviour/Continuum>>

Detailed synopsis

Five years ago, documentary filmmaker Shalom Almond discovered she had inherited an eye disease called Retinitis Pigmentosa, or RP, a degenerative condition that sees adults initially lose their night vision, then slowly their peripheral vision until they eventually go blind. Shalom inherited RP from her mum Brenda, so there is a 50 per cent chance she could pass on the disease to a child.

Now that Shalom and her husband Osker have decided to start a family, years of seeing Brenda struggle with the disease has meant they would do anything to stop passing RP down the family line. They decide to try a type of IVF called Preimplantation Diagnosis or PGD, a procedure that can help screen for genetic diseases, but which also stirs a minefield of ethical dilemmas.

After five failed attempts, the cost and stress of PGD leaves Osker wanting to abandon the treatment, and Shalom is having doubts too. Osker wants to have a baby naturally and bear the consequences, but Shalom is acutely aware of her mother's thoughts on the subject. Brenda believes it is irresponsible and unethical to knowingly risk passing on a disease when you have a chance to stop it. Brenda wants RP to end – and she needs Shalom to end it.

This next IVF cycle could be their last. While anxiously awaiting results, Shalom wants to know more about what's happening to her embryos. The process seems so abstract – what really goes on in the genetics lab behind closed doors? And how



Now that Shalom and her husband Osker have decided to start a family, years of seeing Brenda struggle with the disease has meant they would do anything to stop passing RP down the family line.

are other young couples, relying on PGD, coping with the complexities? Shalom meets embryologist Hamish, and a young couple – Carly and Gareth – who have also been through PGD. Their reflections help ease some of Shalom's anxieties, but she still has some big questions to tackle with her family.

Then, suddenly, the rollercoaster ride is over: Shalom is finally pregnant, but not quite the way she'd planned. Despite all their attempts, the genetic outcome of Shalom and Osker's baby is still uncertain. Shalom's journey now takes on a new meaning as she and Osker must make a decision about whether to test their baby after he or she is born. Will Shalom have the support of her extended family? Will Brenda finally accept that Shalom must also live with RP, even potentially repeating her mother's dilemma? And can their 'love heart' baby help heal their family?

Before viewing

Discuss with students their prior knowledge of genetic inheritance and attitudes towards IVF and embryo screening before watching *Love-Heart Baby*. Ask students to note any information that is they find disturbing/new/interesting or that they wonder about while they are viewing the film.

Focus attention on the topic of the film by asking:

1. What do you think it would be like to pass on a genetic disorder to your child?
2. Do you have any opinions about IVF or Preimplantation Diagnosis or PGD? (NB: Do students mention 'right to life' negative news stories about IVF?)
3. What do you know already about genetic disorders? What firsthand experience do students have of people suffering from inherited diseases?
4. How many people do you think use IVF each year?



Left: Shalom Almond
Above: Shalom with embryologist Hamish



Viewing questions and discussion starters

The following is a list of possible discussion starters that teachers can consider using depending on their study focus in using the program. The questions are divided into four groups covering about a quarter of the program each. This could be used to divide the viewing into these four sections and stop the film to discuss each section.

The questions are timestamped for ease of reference, allowing efficient review of pertinent sections. These starters link directly to the activities that follow in this study guide.

These questions could be given as a handout with spaces for students to record responses during viewing.

Responding

Section 1 (0.00–7.00 minutes)

– Introduction to ‘the issue’

1. What happens to a sufferer of retinitis pigmentosa? (2.36)
2. How does PGD work? (4.17)

Section 2 (7.00–10.35) – The emotional strain

3. What does Shalom’s mother think and feel about the disease? (7.00)
4. Why do you think they decided to try one more time to create a good embryo? (7.26)
5. What are some of the moral problems involved? (8.42)

6. What is cystic fibrosis and how does it affect a person? (10.15)

Section 3 (10.35–17.11)

– Implanting decisions

7. Do you think you would have decided to use the embryos that Shalom and her husband did? (11.04)
8. What did Shalom’s mother decide to do rather than have more children? (12.33)
9. How is a biopsy done on an embryo in PDG? (15.21–17.11)

Section 4 (17.30–26.33) – Living with pregnancy and genetic disorders

10. What is the dilemma that Shalom faces after getting pregnant? (18.57)
11. Do you think you would test the child if you were Shalom? (22.48)
12. Do you think you would regret having a child with a genetic disorder, knowing it could be avoided? (23.44 – 26.00)

Shalom filming her family





'My favorite part about making the film was having the chance to connect with other couples going through PGD.'

Shalom Almond

the film before completing the worksheet for themselves.

After completing worksheet

- Share responses and discuss.
- Make a class list of the genetic science terms and ideas that students need to know before they can understand the content of the film.

WORKSHEET 2 ACCOMPANIMENT

What do you know about genetic inheritance and disorders?

Suggested class time allowance: 1 hour

Curriculum focus: Science: Biological sciences; General capabilities: Critical and creative thinking

Grouping strategy: 1:2:4

The task: Use statements from the *Love-Heart Baby* film and press kit to explain (a) the science and (b) the ethical issues behind genetic inheritance and disorders.

This list of quotes is ideal for use to test for and expand basic knowledge of genetic inheritance, disorders, IVF, and genetic treatments that is developed from viewing the film.

Focus areas for class discussion could include:

- How are characteristics inherited?
- What is a genetic disorder?
- What is retinitis pigmentosa?
- What other inherited disorders might be screened for in this way?
- What are the differences between IVF and PGD?

Activities

WORKSHEET 1 ACCOMPANIMENT

What do you know, think and feel?

Suggested class time allowance: 1 hour

Curriculum focus: Science: Biological sciences; Arts: Media arts; English: Literature; General capabilities: Critical and creative thinking, and Ethics

The task: Working in pairs, students could fill out the worksheet after watching the film for the first time.

What to do:

Prior to handing out worksheet

- Read the comment below by Shalom Almond about the film, which is recorded on the worksheet.

My favorite part about making the film was having the chance to connect with other couples going through PGD. Until making the film, I had never spoken to anyone who was going through PGD or had successfully produced a baby from the process. During the production stage I met with several women who were going through PGD and who shared their stories with me. I would have loved to have featured them in the film, but unfortunately most of them were not prepared to speak on camera – which in itself says a lot about how important it is to open up dialogue about PGD.

- Discuss the comment as a class and ask students to share their own responses to

Above: Shalom with her husband Osker
Below: Shalom in the lab with Hamish



What to do:

- Group of one – Working by yourself, read the quotes and comment on each statement on the worksheet.
Group of two – Compare your comments with a partner. Are your comments on each statement on the worksheet similar?
Group of four – Pairs join up to make groups of four and compare comments. Each student can add to their comments on their sheet using information from the group discussion.
- Working in the groups of four, select one of the quotes from the worksheet to find supportive evidence for ideas from what is remembered from the film.
Make a list of questions the group has about genetics science and/or technology.
- Research task – Choose another genetic disorder that can be screened for research, using resources listed in this study guide as a starting point.

WORKSHEET 3 ACCOMPANIMENT

Modern genetic technology and people: Personal and ethical dilemmas

Curriculum focus: General capabilities: Critical and creative thinking, and Ethics

Review and discuss the section of film that described the process of PGD as a class. (*Timestamp start: 04 17 02*)



PGD works like this. I inject hormones that make me produce more eggs. My eggs are then collected and fertilised in the lab to become embryos. Next they remove one or two cells from the embryos and check them for the RP gene. If the lab can identify a good embryo it's transferred back into my body, or so the theory goes.

The task: Aim: This activity asks you to explore the personal responses to genetic disorders and impacts of new genetic technologies.

This worksheet provides opportunity for students to explore the idea that PGD can be performed for most single gene disorders for which a specific gene fault (mutation) has been identified. These include conditions such as HD, myotonic dystrophy, cystic fibrosis, thalassaemia and haemophilia as



Left: Shalom with her sister and nieces
Above: Shalom with her mother, grandmother, sister and nieces



Left: Shalom filming her sister and niece
Below: Shalom with her camera

‘Initially, the idea of turning the camera on myself seemed all too confronting.’
Shalom Almond

well as RP, the genetic disorder that is central topic of this film. It can also be used to detect chromosome abnormalities such as Down syndrome.

What to do:

1. As a class, discuss the process of PGD expressed in the film.
2. Hand out the worksheet and ensure students understand what is required to fill in the table.
3. Students may need to search the film for the terms listed to complete the table.
4. When the worksheets are complete, share the students’ own expressed ideas and how the film may have influenced them.

WORKSHEET 4 ACCOMPANIMENT

A short genetics documentary

Curriculum focus: Science, English & Media Arts: The making of a documentary about a modern ethical decision related to genetic screening

Initially, the idea of turning the camera on myself seemed all too confronting and would inevitably add extra pressure to an already stressful process. But one year and thousands of dollars later, I decided I did want to tell my story on camera after all. After five failed attempts, PGD was putting huge emotional pressure on my relationship with Osker, and we were both seriously questioning whether we could continue on this path.

What to do:

Prior to handing out worksheet

Discuss: What special risks do you think may be involved in making this human documentary?

1. How is the ‘story’ presented in *Love-Heart Baby*?
2. How important is the range of voices in the storytelling to the success of this film?
3. How is the narrative constructed in *Love-Heart Baby*?

Consider the following questions:

- a. How long do you think a film like this might take to make?
What minor and major difficulties might have occurred? How would the filmmaker ‘adjust’ when things did not go to plan or the unexpected occurred?
- b. The filmmaker must anticipate events outside his/her control and make allowances for them. For instance – Do you think that Shalom and her husband would have predicted what they did? How important was it to actually see footage of Shalom having treatments?
- c. How important was the filming of interviews with Shalom’s family to the documentary? How did she maximise the dramatic impact of the sequence of events?
- d. What would be an unforeseen event that would mean that no amount of adjustment to the narrative or editing could rescue the story?



Worksheet 1



WHAT DO YOU KNOW, THINK AND FEEL?

NAME(S) _____

Filmmaker Shalom Almond says:

My favourite part about making the film was having the chance to connect with other couples going through PGD. Until making the film, I had never spoken to anyone who was going through PGD or had successfully produced a baby from the process. During the production stage I met with several women who were going through PGD and who shared their stories with me. I would have loved to have featured them in the film, but unfortunately most of them were not prepared to speak on camera – which in itself says a lot about how important it is to open up dialogue about PGD.

(Love-Heart Baby press kit)

- Why do you think many women may not have wanted to be interviewed for this film?

- What was a positive highlight in the film for you?

- What is the central issue or problem Shalom Almond faced as presented in *Love-Heart Baby*?

- List at least four aspects of genetics science and technology that are described or used in the film.

- What do you now know about IVF and PGD that you didn't before watching the film?

- What are some of the different social, moral and/or ethical positions presented in *Love-Heart Baby*?

- How do you feel about the use of genetic testing, IVF and PGD?

Worksheet 2

ABOUT GENETIC INHERITANCE, GENETIC DISORDERS AND MODERN TECHNOLOGY

NAME(S) _____

The task: Read and comment on the five statements from Love-Heart Baby film and press kit below. List below each one your ideas on the (a) science or (b) ethical issues related to each statement.

1. RETINITIS PIGMENTOSA

It's always been like a big black cloud just coming over me and squashing me to the ground. It's always with me. Every second of the day. In the house. In the kitchen. I put the glass down and I can't see where it is. I'll wash the dishes and I can't find the sponge. All things. I have to stand six feet back to see or find things. I lose things all the time. I knock things. I break glasses all the time. I have bruises all the time. I walk into things. (Brenda, Love-Heart Baby, Timestamp: 6.36)

a) the science

b) ethical issues

2. PGD TECHNIQUE

PGD works like this. I inject hormones that make me produce more eggs. My eggs are then collected and fertilised in the lab to become embryos. Next they remove one or two cells from the embryos and check them for the RP gene. If the lab can identify a good embryo it's transferred back into my body, or so the theory goes. (S Almond, Love-Heart Baby, Timestamp: 4.17)

a) the science

b) ethical issues

3. IVF

All couples requesting PGD must first undertake an IVF cycle to stimulate the woman's ovaries to produce a number of eggs. These eggs are collected and fertilised using the male partner's sperm. The resulting embryos are cultured in the laboratory. Embryo biopsy is performed on either Day 3 or Day 5/6 after egg collection. The embryos are kept in culture while the testing of the biopsied cell/s proceeds. Following PGD testing, unaffected embryos are transferred to the uterus. (Love-Heart Baby press kit)

a) the science

b) ethical issues

4. PGD USES

PGD testing may be appropriate for:

- Couples at risk of passing a single gene disorder on to their children
- Couples at risk of having children with a particular X-linked disorder
- Couples where one partner carries a balanced chromosomal rearrangement
- Couples with advanced maternal age (>36)
- Couples who have experienced repeated miscarriage
- Couples who have experienced repeated IVF failure

- Couples who have previously had a pregnancy with a chromosomal abnormality (Love-Heart Baby press kit)

a) the science

b) ethical issues

5. DESIGNER BABIES

PGD raises numerous ethical issues as it has the potential to screen for genetic issues unrelated to medical necessity, such as sex, intelligence and beauty, and against perceived negative traits such as disabilities or sexual orientation. The prospect of a 'designer baby' is closely related to the PGD technique, creating a fear that increasing frequency of genetic screening will move toward a modern eugenics movement. Most of the medical community has regarded this type of 'designer baby' testing as a counterintuitive and controversial suggestion. (Love-Heart Baby press kit)

a) the science

b) ethical issues

Worksheet 3

MODERN GENETIC TECHNOLOGY AND PEOPLE: PERSONAL AND ETHICAL DILEMMAS

Name(s) _____

Filmmaker Shalom Almond wants a baby free from her family's history of blindness, but while modern medicine might offer that possibility, there's no manual for the moral minefield that comes with it.

Aim: This activity asks you to explore the personal responses to genetic disorders and impacts of new genetic technologies.

WHAT TO DO:

- Complete the table by using sections of the film in which various people comment on their attitudes towards what Shalom and her husband are doing to screen their embryos. Record at least one comment in column one 'In the film' that falls into each of the four topics listed. Record in the second column the reasons or evidence people give for their attitudes. In the third column, record Shalom's response to the idea presented.
NB: You may need to review sections of the film to find relevant details.

2. Our Comments/Responses

After considering these various responses, and using the knowledge you now have about the technology, record your own personal response/feelings about the ethical issues involved.

I/We think ...

Do you think your ideas changed much in viewing the film, and what parts of the film influenced you most?

TOPIC	1. IN THE FILM	2. REASONS	3. SHALOM'S COMMENT
Retinitis Pigmentosa			
IVF & PDG			
Passing on a genetic disorder			
Genetic technology			
(your own topic)			

Worksheet 4

MAKING A SHORT GENETICS DOCUMENTARY

GROUP NAME: _____

Purpose: This activity asks you to make a short (1–5 minute) documentary about an aspect of genetic inheritance, genetic disorders or a modern ethical decision related to genetic screening

Group size:

Work in a group of three or four

Time allowed:

2–4 hours as negotiated



WHAT TO DO:

1. Choose one or more of the points below as a focus for making a short documentary (Circle the points you select):

- Describing the role of DNA as the blueprint for controlling the characteristics of organisms
- Using models and diagrams to represent the relationship between DNA, genes and chromosomes
- Recognising that genetic information passed on to offspring is from both parents by meiosis and fertilisation
- Representing patterns of inheritance of a simple dominant/recessive characteristic through generations of a family
- Predicting simple ratios of offspring genotypes and phenotypes in crosses involving dominant/recessive gene pairs or in genes that are sex-linked

- Describing mutations as changes in DNA or chromosomes and outlining the factors that contribute to causing mutations
- Investigating the applications of gene technologies
- Considering the use of genetic testing for decisions such as genetic counselling, embryo selection, identification of carriers of genetic mutations and the use of this information for personal use or by organisations such as insurance companies or medical facilities

2. Research information and how you might explore this in a documentary format. Record sources used.

3. Explore possible methods that could assist in making a factual story or documentary.

Hint: Consider using one or more of the following methods:

- Creating a storyboard of drawings explaining an aspect of genetics or genetic disorders
- Creating a genetics family history (may be unrelated to disease)
- Scripting and videoing a one-question interview with a group of people about knowledge of genetics
- Using stop frame photography of models (see <http://slowmation.com.au>) or a storyboarding computer program to assist in creating an animation.

Watch examples of how to present information in one minute. Discuss what works well that could be used in making their own videos.

(<http://60secondscience.net/the-details/the-rules/>)

4. Plan your 1–5 minute documentary using your chosen method on your chosen topic

5. Get approval before going ahead: Write a brief synopsis of the methods and intention or purpose of the documentary, film, animation or computer graphic you want to make for approval by your teacher.

Online resources for students and teachers

Genetic disorders

Genetics education and genomics for health

<<http://www.geneticseducation.nhs.uk/learning-genetics/common-genetic-conditions/retinitis-pigmentosa.aspx>>

Retinitis pigmentosa

Retina Australia NSW Inc

<<http://retinaaustraliansw.com.au>>

Retinitis pigmentosa – Genetics Home Reference

<<http://ghr.nlm.nih.gov/condition/retinitis-pigmentosa/>>

Foundation fighting blindness

<http://www.blindness.org/index.php?option=com_content&id=50&Itemid=67>

Genetic screening

Science daily: New Preimplantation Genetic

Screening Method Can Predict Chromosomal Abnormalities, Study Shows Science Daily (July 13, 2010)

<<http://www.sciencedaily.com/releases/2010/07/100706103606.htm>>

BBC news: Egg screening test 'predicts genetic problems' (28 Jun 2010)

<<http://www.bbc.co.uk/news/10433577>>



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