Activism through Documentary Film

Isabel Stenzel Byrnes
Genetic Alliance

Posted in the Resource Repository at:
The Power of Two:
Translating our Life Experience into Advocacy

Isabel Stenzel Byrnes, MSW, MPH
Genetics Alliance Webinar
May 26, 2010
© 2010 All rights reserved
What is Cystic Fibrosis?

- Genetic disease
- Affects 30,000 Americans
- Affects lungs & other organs
- Requires daily care
- Is progressive
- Shortens lifespan
- Rare in Asians

The genetic defect underlying cystic fibrosis disrupts the functioning of several organs by causing ducts or other tubes to become clogged, usually by thick, sticky mucus or other secretions.

**AIRWAYS**
Clogging and infection of bronchial passages impede breathing. The infections progressively destroy the lungs. Lung disease accounts for most deaths from cystic fibrosis.

**LIVER**
Plugging of small bile ducts impedes digestion and disrupts liver function in perhaps 5 percent of patients.

**PANCREAS**
Occlusion of ducts prevents the pancreas from delivering critical digestive enzymes to the bowel in 85 percent of patients. Diabetes can result as well.

**SMALL INTESTINE**
Obstruction of the gut by thick stool necessitates surgery in about 10 percent of newborns.

**REPRODUCTIVE TRACT**
Absence of fine ducts, such as the vas deferens, renders 95 percent of males infertile. Occasionally, women are made infertile by a dense plug of mucus that blocks sperm from entering the uterus.

Born in 1972 to Immigrant Parents
Diagnosed with CF at Birth
Treatment Burden

3-4 hours per day
Frequent Hospitalizations
Expressing our struggles through writing and art
Growing Older with CF Wasn’t Easy: The CF Community Offered Support, Education and Hope
The Gift of Life: Lung Transplantation
Ana 6/14/00 & Isa 2/6/04
Life After Lung Transplantation...

Is miraculous!
Is unimaginable!
Is freedom!

Support organ donation
www.donatelifecalifornia.org
Or
www.donatelifene.net
Healing from our Journey: Giving Back

- Writing Our Book
- Mentoring
- Educating Students and Health Care Professionals
- Volunteering for organ donation
- Speaking at Pharma
- Facilitating support groups
- CF Community Programs
- Participating in Awareness Events
- Helping to organize Retreats & Conferences
- Writing for Newsletters
The Power of Two:
A Twin Triumph over Cystic Fibrosis
A Memoir by Isabel Stenzel Byrnes and Anabel Stenzel
University of Missouri Press 2007
Our memoir was translated into Japanese and released in Japan in Sept. 2009
Iwanami Shoten Publishers
www.iwanami.co.jp

This led to a month long book tour in Oct. ’09 to promote organ donation and CF awareness in Japan
Main Messages in “The Power of Two”

• The truth about CF in our generation and its impact on family
• Give thanks
• Perseverance
• The gifts of illness
• The importance of community support
• Culture influences how we cope with illness
• Raise awareness of CF and organ donation
Why Japan?

• As a developed country, Japan has the lowest rates of organ donation in the developed world
• Organ donation is very controversial in Japan due to different cultural beliefs
• There has been recent legal momentum for slow change
The Japanese CF Community

- The life expectancy of Japanese CF patients is only 15 years

- In June 2009, “The Committee to Enable CF Treatment” was created
Why Is Organ Donation So Controversial in Japan?
“Trying to promote organ donation in Japan is like sprinkling a few drops of water on a desert and expecting a tree to grow.”

Mr. Yoshi Nomura, two-time liver recipient (in Texas), head of TRIO Japan
Social Issues

• Stigma and shame for illness
• Lack of patient advocacy
• Conservative medical system
• Distrust in the medical system (1968 Wada case)
• Lack of funding and infrastructure supporting transplantation
Cultural & Religious Beliefs

- The dead body should not be disturbed and should be cremated whole
- One should accept the natural order of death and transplant goes against that order
- “Soto” versus “uchi” (outsiders versus home)
- Giving is based on reciprocity and “ongaishi” (obligation to return the favor)
What are Japanese transplant candidates doing?

• Waiting a long time for transplants
• Fundraising to pay for transplants abroad
• If possible, finding living related donors from parents
• Resigning to “shikataganai” (hopelessness)
• 27 people die each day due to a lack of organs in Japan! (18 die a day in the USA)
What Were Our Goals?

• To create a cross cultural dialogue about organ donation and patient advocacy
• To represent a country where people with disabilities/chronic illnesses have equal access and opportunity
• To show the benefits of organ donation and transplantation from the recipient’s perspectives
• To increase awareness about cystic fibrosis in the Japanese population
Stay Tuned…

The Power of Two Movie –
A documentary film to examine the cultural influences on organ donation, CF, patient advocacy and the miracle of breath

To Be Released January 2011

www.thepoweroftwomovie.com

Check out our website for preview videos and to support The Power of Two Film Project!
Treatments & Hospitalizations