

#### Phyllis M. Wallace, DrPH, MSEd, CHES pmwallace03@yahoo.com 5124.0 Wednesday, November 7, 2007 12:30 - 2:00

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Illustrate the need for adulterated injection liquid silicone (AILS) harm reduction interventions and policy

Highlight a public health threat among transgender youth

# The indication of harm, not the proof of harm, is our call to action.

~ Be Sargent, muralist

11/21/2007

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#### 2001 Vera Lawrence

#### 2003 Delfino Gonzalez

#### 2003 San Chiem

#### 2004 Andre Jeter

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# **Background on Silicone** (Si)

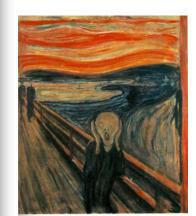
- Elastic polymer, R-O-Si-C-R
- Viscous, sticky fluid
- Industrial grade silicone cosmetic filler for physical augmentation
- Not encapsulated
- Injected directly into the body
- Operator lacks clinical/medical training
- Widespread US and other countries

(Rodriquez 1989; De Gado et al. 2006)

# **Challenges**

#### Lacking

- Operationalization <- no universal language</p>
- Prevention interventions
- Public health literature to support anecdotal experiences
- Cost-effective means for safer transitioning
   (i.e., endocrine hormones, SRS, plastic surgery)
   Morbidity and mortality data (e.g., ER, ME, LE)



# First, Do No Harm

#### **NO MEDICAL SAFEGUARDS**

- No practice guidelines
- No initial consultation/evaluation
- No health history or prescreening
- No tests for allergic reactions or contraindications
- No patient education
- No routine monitoring

www.answers.com/topic/the-scream 11/21/2007



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### **Trajectory of Si in the Body**

#### Broad overview

In the presence of large amounts - Si enters the body, engulfed by macrophages, inflammatory response activated, infiltrates course through the body negatively affecting cells and tissues; eventual accumulation in lung tissues, loss of air exchange, lack of O<sub>2</sub> in the blood, resulting in respiratory failure and death

(Vilde et al. 1983; Duong et al. 1998; Hexsel et al. 2003; Schmid et al.2005)

# **Health Issues with Injection Si**

- Often given in large doses (Hexsel et al. 2003; Orentreich et al. 2004 [0.01 cc ✓ dose])
- Impossible to remove
- Illegal practice
- Inappropriate methods
- Unhygienic conditions

### **Health Issues with IS**

- Underground, secret practice
- Respiratory ER 7 failure 7 death
- No long-term impact studies on AILS in the human body

(Kopf 1966; Ellenbogen et al. 1975; Chastre et al. 1983, 1987; Lai et al. 1994; Chung et al. 2002; Duffy 2002; Rapaport 2002; Rosioreanu et al. 2004; Fox et al. 2004; Gaber 2004; Komenaka et al. 2004)

Webb. (1997). Cleopatra's needle: The history and legacy of silicone injections. Boston, MA. http://leda/law.harvard.edu/leda/data/197/mwebb.html 11/21/2007

### **Silicone Syndrome**

- fever
- edema
- shortness of breath
- inflammation
- chest pain
- viral or bacterial infection
- granuloma

### **Silicone Syndrome**

- scleroderma
- neuropathy
- keloids
- migration
- rheumatic symptoms
- synovitis
- severe autoimmune and connective tissue disorders, for example

(Kopf et al. 1966; Ellenbogen et al. 1975; Chastre et al. 1983, 1987, Bigatà et al. 2001; Duffy 2002; Schmid et al. 2005)

### **Pulmonary Silicone Embolism**

#### Congestion

- Pulmonary hemorrhage
- Acute pneumonitis
- Diffuse alveolar damage
- Bacterial pneumonia

(Chastre et al. 1983; Coulaud et al. 1983; Jung, et al. 1993; Chen et al. 1993; Lai et al. 1994; Matsuba et al. 1994; Doug et al. 1998; Kang et al. 1999; Villa et al. 1992; Chung et al. 2002)

### **Impact of Si Use**

Ellenbogen et al. (1975)

- > 21 transsexual was injected by unlicensed operator w/ AILS; injected in the shoulder, nose, jaw, breasts; developed fever, malaise; dx. granuloma
- > 28 transsexual was injected developed nodules and granuloma

### **Impact of Si Use**

Duong et al. (1998)

African-American MtF, St. Joseph Hospital, Chicago; shortness of breath 2 days post sub-Q AILS injections (she was also being injected with bootleg estrogen hormones); HIV+

### **Impact of Si Use**

#### Fox et al. (2004)

> 29 MtF injected in breasts; presented at Columbia Presbyterian Medical Center, NY w/ low grade fever, breast abscesses, hirsutism (presence of excessive bodily or facial hair), edema of the joints, wrists, knees, ankles, and feet; dx. Mycobacterium abscessus

### **Historical Literature Review**

	Report Type	No.
	Clinical	25+
	Trans health studies	4
	Anecdotal	2
	Trans magazines	2
	Local news	7
	<b>Dissertations</b> (Tilleman 1997; Webb 2005; Wallace 2007)	3
	Health study inc. Si	4
11/21/2007	Public health	0

### **Drug Surveillance**

AILS use is not reportable data

- Health department social epidemiological data
- SAMHSA DAWN (Drug Awareness Warning Network)
- CDC's MMWR

*"Reporting is fundamental to detecting patient safety problems." WHO* 

### **WHO Patient Safety Resolution**

- Serious global public health issue
- Need for improving patient safety
- Resolution WHA55.18: Quality of Care: Patient Safety (18 May 2002)
- World Health Assembly Alliance launched October 27, 2004 in WDC



"In some countries, the proportion of injections given with syringes or needles reused without sterilization, is as high as <u>70%</u>."

"Each yr., <u>unsafe injections cause 1.3 million</u> <u>deaths</u>, <u>primarily due to transmission of</u> <u>blood-borne pathogens such as HBV, HCV,</u> <u>and HIV</u>."

World Health Organization. (n.d.). *10 Facts on Paitent Safety*. Retrieved October 1, 2007, from http://www.who.int/features/factfiles/patient\_safety/en/index.html

### **Need for Precaution & Prevention**

#### Risk prevention

- Ethical responsibility of patient safety (particularly for vulnerable subgroups)
- Unlicensed operators must be held responsible for burden of disease and putting the public at risk for financial gain

• "Duty to care" CHES, HED, PHE, etc.

# **Next Steps**

#### Applied Health Studies

- APHA (1999) Policy #9933
  - Need for medical provider training
  - Need for trans inclusion in research studies
- Theory-based/competency-based community interventions
  - Employ PATCH or CbPR models
- Inclusion in MMWR and DAWN reports

# **Next Steps**

US and transcontinental directory of trans-friendly plastic surgeons, family practitioners, behaviorists, and financial planners

Awareness of trans illness and death correlate of AILS to inform health promotion strategies

### **Follow-up Action Steps**

What can be done right now!

Post-conference round table workshops
Develop a health department task-force
Support AILS harm reduction policy
Advocate for safer, cost effective physical enhancement procedures
Engage trans youth and emerging adults



# **Follow-up Action Steps**

#### Long term planning ...

- Government funding for AILS epi studies
  - safe(r) transitioning alternatives
- CE for health providers and graduate allied health students
- In-service for ER staff on care procedures for trans youth presenting with AILS complications
- Inform USPHS, USDHHS, NIDA, CDC, USDOJ via policy and alert campaigns for descriptive data (grassroots)

#### **Resources for Scientists and Providers**

**Holman**, CW, & Goldberg, JM. (2006). Ethical, legal, psychosocial issues in care of transgender adolescents. *International Journal of Transgenderism*, *v9*, 95-110. doi:10.3100J485v09no3\_05

**Wallace**, PM. (2007). Mixed methods needs assessment to determine prevalence of Injection silicone behavior among transgender youth: Insights form interviews and surveys (Doctoral dissertation, Walden University, 2007). Dissertation Abstracts International, 41. (UMI No.3251365)

#### **Books**

Cromwell, J. (1999). Transmen and FTMs: Identities, Bodies, Genders, and Sexualities. Chicago, IL: University of Illinois Press.
Meezen, W, & Martin, JI. (2003). Research Methods with Gay, Lesbian, Bisexual, and Transgender Populations. NY: Haworth Press.
Sears, JT. (2005). Gay, Iesbian, and transgender issues in education: Programs, Policies, and Practices. NY: Haworth Press.





Purpose of slides are for information sharing with APHA workshop attendees, to increase awareness of IS and associated health complications among trans populations. This report does not intend to diagnose, treat, or offer medical advice. Contact your medical provider or T-friendly clinic with treatment questions or side effects associated with IS. PMW