… a government

of the people,

for the people,

by the people …

Even in health care!

Comments from the

Committee of Ten Thousand

Washington, DC

HHS Advisory Committee on

Blood Safety & Availability

September 19-20, 2005

ACBSA

- The IOM recommendation regarding establishment of the committee
- The mission
- The client: Secretary of DHHS
- Has the ACBSA lost touch with the client?
- If so, how is that client / provider loop to be nurtured?

ACBSA

- A unique history – do seniors at HHS clearly understand this history, and what was accomplished between government and all stakeholders
- Resisting the logic of power and narrow professionalism
- Nurturing the ‘all stakeholders, grass roots community’ participation model

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ACBSA

- Enhancing and nurturing communication loops between all stakeholders
- Willingness to trust each community's commitment to the process
- Principled dialogue and criticism from all seated at the table
- Eyes on the prize: keep all on-focus on the goals: policy recommendations for a safer and more available blood supply.

How the Committee Works

Other:
Home Care /
Plasma Distributors

Federal Government

Testing / Devices Mfgrs

ACBSA Inputs
and Members

Consumers

Blood Bankers

Fractionators

How it Should Work

Federal Government

State Public Health

Fractionators

ACBSA

Blood Banks

Plasma Distributors

Blood Recipients

Plasma Recipients

Blood Donors

Testing / Devices Mfgrs

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Stakeholders in Blood Supply

Government
HHS: FDA / PHS / CDC / NIH / CMS

Blood Banking	Manufacture	Health / Medical	Community
AABB	Fractionators	Home Health Care	End Users
ABC	Source Plasma	Clinicians & Treaters	Advocates
Red Cross	Biotech Cos.	Psycho-Social Care	
		Research	

The Community's View of the Mission

- To Coordinate the federal government's response to threats to the nation's blood supply, using the inter-agency tools at its disposal.
- To evaluate supply and allocation of blood / blood product resources ensuring available, safe supply for communities and individuals in need.
- To bring the relevant federal agencies together to ensure safety to the greatest degree available, and ensure availability through strategic planning for today and the future.

The Model for Positive Change

WHAT WE KNOW WORKS

- The IOM Report – Community involvement in the preparation and direction of the study
- Establishment of the ACBSA and the presence of grass roots community representatives at the table
- Inter-stakeholder dialog and discussion
- Interactive learning that occurs on all sides of the table through respectful and thoughtful dialog and discussion
- Openness of government to allow and nurture this creative and unique process to go forward

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The Model for Positive Change

- All parties working together to ensure adequate funding for the continuation of the interactive and inter-stakeholder process
- Historical continuity – not viewing the mid-1990's as a single moment but viewing the period as the beginning of an ongoing process

The Model for Positive Change

THE MODEL

• Continued willingness to resist the logic of power and professionalism in order to keep the process alive and vibrant

• Government and community support for grass roots advocacy going forward

• CDC's 'state / infected / affected' model from HIV Prevention – California: the communities engage

Learning from the Past

- **<u>HIV</u>**: It's not ***<u>IF</u>*** new / unknown pathogens will present themselves, but when.

  The issue is coordinated response and the time frame thereof.

  Inaction ultimately leads to serious injury and potential death for end users.

  Openness to new approaches and the application of surrogate markers where direct ones don't exist (HBV for HIV to defer donors in the 1980's).

  Principled self-criticism as very distinct from denial and obfuscation.

Learning from the Past

- **HCV**: Where did this epidemic originate?

  How do we get such high incidence / cases – roughly 4 million – and we still have not understood the landscape of 'from where'?

  Long-term historical decisions and assumptions were made and never revisited

  'Acceptable Risk:' Concurrence between Government, industry, medical community.

  What could possibly constitute an acceptable risk?

  Decisions regarding risk must include end users / consumers.

Learning from the Past

- **<u>CJD, vCJD</u>:** The absence of evidence is not the evidence of absence.

  Indifference or hostility to views outside of the accepted "American" perspective leads to critical inaction.

Grass Roots Advocacy

- The object of the system evolves into the subject of change; those involved becoming agents of change
- Direct access to end users / consumers
- Clear views of the material conditions on the ground in various end user communities
- The ability to present solid anecdotal information and data regarding end user communities

Grass Roots Advocacy

- Creative thinking, not narrowed by traditional professional norms and boundaries
- Peer advocacy programs that emerge from the conditions on the ground in end user communities
- Needs assessment from those who are actually in need

Grass Roots Advocacy

- The creation of interdisciplinary approaches better suited to the natural conditions than traditional models may be
- A well-honed psycho-social program that addresses the emotional / soul needs for end user communities.

Grass Roots Advocacy

- An active empowered model that provides quality input to the process that is the result of living with hemophilia, HIV, HCV
- Structures, such as COTT's national working groups, that give voice to the individuals / families directly impacted by the decisions of the ACBSA through national conference calls

"I was seven years old when I found out that my Dad has HIV. For about three years after I found out I did not sleep much and when I did, I woke up crying because I thought he would die during the night."

- Laubua Acuna-Dubin, 12 years old