

*Advisory Committee on
Blood Safety and Availability*

CONSUMER ADVOCACY APPROACH
TO CURRENT AND
EMERGING INFECTIOUS PATHOGENS

Shannon Penberthy
MARC Associates, Inc.
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Blood Safety Role of Consumer Organizations

- **Advocacy**
 - U.S. Congress and Agencies
 - Blood Safety Committees
 - Manufacturers
- **Information**
 - Consumers
 - Medical Providers

Safety Activities of Consumer Organizations

- **Step One: Monitoring**
 - U.S. Health Agencies
 - Manufacturers
 - News Reports
 - Consumers
 - Physicians
 - Foreign Governments

Safety Activities of Consumer Organizations

- **Step Two: Investigate**
 - Task forces and committees
 - Consumer and medical input
 - Consult with Federal Agencies (FDA, CDC)
 - Increasingly consult with consumer and government organizations in other countries

Safety Activities of Consumer Organizations

- **Step Three: Communicate**
 - Medical Advisories
 - Electronic Alerts
 - Articles in Electronic and Print Publications
 - Chapter and Provider Mailings

Safety Activities of Consumer Organizations

- **Step Four: Advocacy**
 - Seek remedies to address specific concerns
 - Participate in Federal Blood Safety Policy discussions and decisions
 - Educate consumers on disease and incident specific information and risks

Safety Concerns of Consumer Organizations

- System Concerns
 - Process is often informal and dependent upon organizational relationships rather than regulation
 - System is not structured to respond rapidly to emergency situations

Safety Concerns of Consumer Organizations

- System Concerns
 - Better understanding of product interactions and outcomes hampered by lack of post-market surveillance
 - Lack of international collaboration

Recommendations from the Consumer Organizations

- Assist consumer organizations in:
 - Raising consumer literacy about blood and blood product safety
 - Informing consumers about disease and incident specific information
 - Providing guidance to consumers and their health care professionals

Recommendations from the Consumer Organizations

- Improve/enforce post-market surveillance
- Enhance patient notification
- Recognize the importance of a multi-disciplinary approach to risk assessment, including bioethics